DOCUMENT RESUME

ED 401 677 EC 305 167

AUTHOR	Devlieger, Patrick; Trach, John S.
TITLE	Ethnographic Study of Transition: On the Threshold of Adult Life.
INSTITUTION	Illinois Univ., Champaign. Transition Research Inst.
SPONS AGENCY	Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	Jul 96
CONTRACT	H023A400700
NOTE	182p.
PUB TYPE	Reports - Research/Technical (143)
EDRS PRICE	MF01/PC08 Plus Postage.
DESCRIPTORS	Biographies; *Case Studies; *Education Work Relationship; Ethnography; Helping Relationship; *Holistic Approach; Individual Development; Individual Differences; *Life Events; Long Range Planning; *Mental Retardation; *Mentors; Qualitative Research; Quality of Life; Secondary Education; Transitional Programs; Young Adults

ABSTRACT

This monograph reports on an ethnographic study of the transition from school to work of 12 individuals with mental retardation. Throughout the book, examples from the lives of these individuals are used to illustrate findings and principles. The first chapter describes the methods of data collection and analysis, which focused on the relation between critical life events and the transition from school to adult life. Chapter 2 presents holistic, person-centered data about the 12 individuals, focusing on the pathways taken, the personal support systems developed, critical life events, expectations of others, and the individuals' own wishes and values. Chapter 3 introduces five skills necessary for successful mentorship in transition, including: (1) problem solving, (2) technical career planning, (3) ability to collect and assess life history information, (4) ability to analyze an individual's adult script and social network, and (5) ability to assess the individual's mediative capacities. Chapter 4 shows how these factors play out in actual lives, in discussion and evaluation of eight life histories. Stressed throughout is the importance of individual differences in planning and implementing transition goals. (Contains 65 references.) (DB)

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Ethnographic Study of Transition

On the Threshold of Adult Life

Patrick J. Devlieger
John S. Trach

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Foreword by
Robert B. Edgerton

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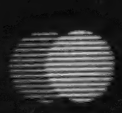

ETHNOGRAPHIC STUDY OF TRANSITION: ON THE THRESHOLD OF ADULT LIFE

Patrick Devlieger
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With the assistance of Gina Hunter de Bessa

July 1996

Transition Research Institute
University of Illinois at Urbana-Champaign

Funding for this research was provided by Grant #H023A400700 from the U.S. Department of Education, Office for Special Education and Rehabilitative Services (OSERS) awarded to the University of Illinois at Urbana-Champaign. Opinions expressed herein do not necessarily reflect those of OSERS.

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We would like to acknowledge the following people for their contributions to the completion of this project. First, we thank Lizanne DeStefano for her consultation in the initial design and editing of the research proposal, critical reading of various drafts of the monograph, and her continued support throughout the project. Next, we thank Gina Hunter de Bessa for her work in collecting data, editing, and pulling together the initial draft of the manuscript. We also thank Kristin Sachs for her editing and computer time; and Merl Levy for the fine job of editing the manuscript.

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Foreword

Robert B. Edgerton

The pivotal role of life transitions is recognized in virtually all societies. Birth, adolescence, marriage, parenthood, death--these among other life changes are very commonly marked by *rites de passage* that dramatize, solemnize and normalize a person's entitlement to a new status in life. They also serve to reduce the anxiety that such transitions may bring about. Although most Western societies have reduced the ritual aspects of these rites, the transitions remain, and one of the most challenging of them is the transition from school to the workplace, and with it the change from childhood to adulthood, dependency to independence.

The transition from school to work is troubled and troubling for almost everyone, but for persons with disabilities it is likely to be particularly problematic. This period not only challenges the individual with a disability, it places new demands on family members, the social support network and the service delivery system. And for persons with mental retardation, this transitional period may be even more troubling than it is for persons with physical disabilities because for such people, no one, including the individual involved, can be quite sure what they are capable of achieving once they leave school.

For this reason, the present monograph is particularly welcome. The transition from school to work for persons with mental retardation has been studied before as authors Patrick Devlieger and John Trach acknowledge, but not with the depth and intensity of the present

work. The need to better understand the needs of persons undergoing this transition and better plan for their futures is clearly a pressing one. Previous work has paid little heed to the crucial role of choice, the existence of differing individual needs and the presence of gender and sub-cultural differences, and no previous work has employed such varied and sophisticated methods of assessing the needs and problems of persons making the transition to adult life.

The authors use traditional anthropological methods of ethnography and life history interviewing along with some new twists on other approaches to provide a commendably holistic, person-centered understanding. Instead of relying on the consensus about a person's future during this transition as it is forged by agency personnel, the authors seek a more complex and predictively-valuable portrait of their lives as developed by triangulating the perspectives of several significant others in their worlds. Anthropologists have long argued that where complex events are at issue--why job performance slips, why a landlord is displeased, why a relationship improves--the reason is seldom simple or singular. There can be a Rashomon effect in which various observers of the event produce radically different explanations of what happened and why. The task of the anthropologist, then, is not necessarily to discover the "true" reality but to acknowledge the presence of multiple realities, all of which interact in influencing the persons involved.

What kind of a person someone is, what cognitive abilities he or she possesses, how they approach life and find satisfaction in it, can be less affected by multiple realities. As much recent research has shown, personal happiness is less a product of recent life events than it is a reflection of one's temperament. Intellectual abilities, too, may be quite stable.

However, in these cases too, individuals with mental retardation do sometimes express one level of satisfaction with life to one person and quite a different level with others. Similarly, social and cognitive competence can vary from one environment to another.

The authors of this volume not only understand these principles, they have designed their research to permit the complexities of the transition to adult life to emerge in a meaningful way, one that presents that meaning through the words of the individuals involved. Their "voices" speak and their lives "come alive." My background as an anthropologist who has used similar methods to study the community adaptation of persons with mental retardation for more than 40 years privileged me to serve as an occasional consultant to this project. Although I fear that I contributed little to this monograph, it will take its place as a valuable source of badly needed information about the life courses of people with mental retardation who are making the transition to adult life.

The monograph begins with a concise and accessible introduction to the methods of data collection and analysis that were utilized. In an effort to devise a long-term perspective on transition planning, the authors undertake an investigation into the relation between critical life events and the transition from school to adult life with the explicit hope that this information will be useful to advocates and service system professionals who may be involved in transition planning.

In Chapter II, the authors critically analyze current transitional planning practice before presenting holistic, person-centered data about 12 individuals in various stages of transition from school to adult life. The data they present illuminate the pathways taken, the personal support systems that develop (called "convoys"), and the critical life events that

influence the life course. They describe the expectations ("life scripts") that significant others have for these 12 individuals, assess their own wishes and values, and point to potential hazards in their future transitions. Finally, they provide a wealth of person-centered information that could be used to improve transition planning process.

Chapter III briefly introduces five mentorship skills that would be required for successful mentorship for transition. In addition to skills in problem-solving and technical career planning, mentors should develop the ability to collect and assess life history information, analyze an individual's adult script and social network, and assess that person's mediative capacities. How these factors play out in the lives of actual individuals is addressed in Chapter IV, where eight life histories are discussed and evaluated. Earlier, the life of Tina, a young woman, had been presented in some detail, emphasizing her successes in overcoming a number of negative life events. Although this portion of the monograph is presented as a final chapter rather than an integral and fully analyzed part of the presentation, it will reward readers who attend to the warnings about the extent to which investigators should remove themselves from a life history presentation as if they had been there and had not colored the information that was provided. The dialectical nature of life history interviewing has troubled scholars for years and will continue to do so. To what extent does any person alter his or her life history in a tactical effort to present a favorable image of self? How does an investigator know?

That issue aside, the life history information that is presented emphasizes the diversity of the individuals involved. There are no stereotypes here. Instead, we are introduced to complex people whose life courses vary greatly. So, too, do the life events that buffer and

buffet them. We meet the people in their lives who matter and those who do not. The material presented is tantalizing brief, of necessity, but a reader can readily understand that a fully developed life history of, say, 400 pages would provide enormously valuable information about an individual but would still be incomplete in many significant ways. A colleague and I recently completed a life history of this length about a man with mental retardation whom a number of investigators had studied for more than 40 years. His life is fascinating, even triumphant as he overcomes difficulties of all sorts to fashion a rewarding life for himself and others who know him. But it is painfully obvious that there are still aspects of the man and his life that we do not understand.

Perhaps that is the message of this monograph as well. If better planning for transition is to take place, this monograph offers many helpful suggestions about what planners need to know if they are to better serve the individuals undergoing transitions, but it would be well to remember that however much the very best planners know about a client undergoing a transition, much will remain that they do not know.

Preface

The study of the lives of persons with mental retardation has evolved over the last several decades. The field has gone from reporting atrocities and experimentation to providing opportunities for participation and soliciting consumer input. In research practices such as institutionalization and behavior modification have given way to ideals such as empowerment and self-determination. Much work is yet to be done, but aspirations and personal rights are widely acknowledged and the person has become the center of planning and service delivery. In this tradition, this monograph attempts the description of a life process, transition, from the perspective of the individual. The intent is to provide a context for the current life circumstances of the participants in this study using ethnographic methods.

The methodology we used and the findings reported were intended for use by researchers and professionals providing services as a way of thinking about transition and a possible structure for collecting information and informing the transition process. Hopefully, within such a structure, accounts from those affected by services will assist in planning the transition of persons with disabilities and in reforming the service systems that affect their lives. Professionals must be prepared to assist, support, and provide opportunities for successful transition. It is a complex process, and case studies are one way to represent that complexity. Our intent is to enable readers to recognize the individual complications with transition, acknowledge them and go forward, rather than see them as impossible barriers to overcome.

The methodology does not afford the opportunity to study a large group of people, nor do the reports presented represent some commonly expected results to be generalized in any way. The limitations of the study might include limited size or convenience of the sample. However, I would venture to guess that those readers with experience in the field know of people much like

those who participated in our study, and can attach the name of someone they have met to the key players in the case studies. Another limitation might be portrayal of context by the researchers. We recognize that our own experiences and values color what we see, and although the reports were created with information obtained directly from participants, some categorization and interpretation by the researchers was unavoidable. In a sense, the research becomes autobiographical; because our analysis is influenced by our own prior experience, values, and knowledge, the reader should be forewarned and interpret accordingly. The important aspect of this monograph is that to the greatest extent possible the participants write the story, and their accounts drove the composition of the case studies of the transition experience.

We hope that the monograph will encourage professionals to be part of peoples' lives with the purpose of creating opportunities, rather than to change people and their lives to conform to existing services systems and traditional outcomes. There may be some common general goals for transition, but the specifics surrounding these goals vary and must be considered in the complex context of each individual life. Just as any graduating class faces a wide array of futures, so should people with disabilities. It would be short sighted to see all these individuals as janitors or food service workers or to assume that they are best served in a large building on the edge of town. Through the stories of the people in this monograph we hope that readers will gain an understanding of the roles of the individual, the family, the community, and the service system in the transition into adult life and use this understanding to improve opportunities and outcomes for persons with disabilities.

John S. Trach, Ph.D., CRC

Principal Investigator

Glossary of Some Terms Used in This Monograph

Convoy - the social group that an individual aligns with during a particular period of life. As the journey of life progresses, a person's convoy changes, especially as the juncture of important life transitions, where important persons may join or distance themselves from a person's convoy.

Cultural Schedule - a normative sequencing of life events as derived at the level of a society (e.g., the recognition that self-reliance and independence is important). This term should be distinguished from a script, which describes the process of a transition at the individual level.

Individual Education Plan - a legal document that outlines the educational program and school services of a student with a disability. The IEP was mandated in the Education for All Handicapped Children Act (P.L. 94-142) of 1975 as a protective measure for parents that secured an educational program and services. In the revisions of P.L. 94-142, the IEP became more prominent as a programming tool and since the revision in the Individuals with Disabilities Education Act of 1990 (P.L. 101-476), it also mandates transition planning.

Life Course - this term is indicative of the complexity of lives in their individual, social, historical, and cultural dimensions. Rather than considering one of these dimensions, life course approaches are more interested in studying intersections between two or more of these dimensions. It should be distinguished from the term "life span," which is more indicative of the biological development of lives. Life course study means an interdisciplinary program in human development that includes approaches of the social sciences and humanities.

Social Realignment **-** the process of developing one's social group as one moves from one stage in life to another. Social realignment is an important marker of the completion of a life transition.

Transition Markers- indicators of the completion of a life transition. Physical markers indicate the movement in space, from one place to another; social markers indicate an important and consistent change of the convoy of a person as a result of a life transition. Both markers can operate independently.

Transition Script **-** a composite picture that describes the process of the transition from school to adult life a person with a disability . Elements in this picture are a script title, which summarizes the overall quality of the transition, and four dimensions of the script. The first describes the intensity of socialization into a service agency, the second the extent to which the transition leads to a more or less radical juncture from the person's past life, the third indicates the amount of release of responsibility from parents, and the fourth refers to the amount of control a person has achieved in various life domains (work, independent living, self/sexuality, peer relations, independent mobility).

CHAPTER I

INTRODUCTION

Project Background: Review of Original Questions

Planning for the transition from school to adult life of an individual with disabilities is a collaborative task of the individual with a disability, special educators, rehabilitation service providers, and significant others, who participate in meetings to develop an Individual Education Plan (IEP), according to the Individuals with Disabilities Education Act of 1990 (P.L. 101-476) (DeStefano & Wermuth, 1992; Wehman, 1992). This research project proposed that a systematic method of collecting information about the individual's life path and anticipating significant events in his or her postsecondary-school experience could enhance the effectiveness of transition planning during IEP meetings. In consequence, we developed a pilot study of an ethnographic research methodology to collect and analyze this kind of information. The potential contribution of this methodology to the effectiveness of the IEP planning process is discussed in this monograph.

Twelve individuals, diagnosed with mild mental retardation, served as the subject population identifying the significant life events that characterize the transition from school to adult life. This group comprised three subgroups of those who made the transition (a) between five and two years ago, and (b) less than two years ago, and (c) those who are in school and are preparing to make the transition. These twelve individuals and their significant others were studied intensively to ensure completeness and to verify all information. Several research questions were central in the study: (1) What are the significant life-course events in

the postsecondary school experience of the individual with mental retardation? (2) How do these events relate to each other? and (3) How does an ethnographic methodology contribute to the enhancement of transition planning during the Individual Education Plan meeting? Three research goals address these questions.

Research Goals

The primary goal was to use ethnographic methodology to study the nature and history of significant life events and significant events that characterize the school-to-adult-life transition (e.g,. Lichtenstein, 1993; Zetlin & Hosseini, 1989). The relationships between life and transition events may appear to be obvious; however, this study focused on the perspectives of the individuals and members of his/her social network rather than that of a service provider. This shift in perspective colored the relationship and provided a more detailed description of events than existed in the literature. In turn, accomplishing this research goal increased our understanding of the directions taken in the lives of those individuals with mental retardation and was compatible with the intent of recent legislation for consumer control, choice, and empowerment. The result of the study was in the life histories of eight individuals, in which critical life events and events related to school-to-adult-life transition are identified (see Chapters II and IV).

A second goal of this project was to study the written Individual Education Plans of the students with mental retardation in order to evaluate their own contributions and those of their significant others, and to assess the nature of transition planning. The description of events and an assessment of transition services have resulted in recommendations that could enhance the effectiveness of transition planning.

Finally, the third goal was to pilot and evaluate an ethnographic methodology in the study of a particular population. Specifically, an ethnographic methodology was used to develop life history analysis, critical event analysis, script analysis, and convoy analysis as a way of making transition planning during an IEP-meeting more effective.

Research Design Methodology

Extensive collaboration with the persons with mental retardation and persons in their social network formed the core of data collection and analysis, and produced a sound basis for informing professionals about current practice. Twelve persons who are mildly mentally retarded were selected to represent a variety of postsecondary and life events. The sample population included males and females, individuals from rural and urban areas, and individuals who were five to two years out of school, less than two years out of school, and currently in school and in the process of planning transition.

The ethnographic methodology piloted in this research project relied on the use of life history interviewing (e.g., Angrosino, 1992; Frank, 1984; Spradley, 1979; Whittemore, Langness & Koegel, 1986) and participant observation (e.g., Edgerton, 1984; Edgerton & Langness, 1978). These data sources enabled us to identify significant events, which were then analyzed in accordance with two procedures. First, significant life events and events in the school-to-adult life transition period were compared and interpreted (see Watson & Watson-Franke, 1985). Second, these events were interpreted in the context of the Individual Education Plan meetings.

While the identification of significant life events provided a starting point for understanding the life histories, critical life events were not evident in some instances. Often, the method did not adequately lead researchers to a full understanding of the directions taken

by the lives of persons with mental retardation. In many life histories, specific "life-changing" events were difficult to pinpoint; many lives appeared uneventful. In the lives of several research participants, specific individuals (usually mothers) rather than events seemed to be a determining factor in the postsecondary school experiences of the individual with mental retardation.

Scripts

Through individuals' narrations of their lives, it became obvious that the roles and life plans that individuals and their significant others created were often more significant to what occurred in the life course (and in transition) than were specific events. Schools and adult service agencies also define roles and expected life paths into which individuals are socialized through the structure and delivery of services. The roles and expectations of the individual with a disability take the form of *scripts*, or narrative models, through which individuals construct their lives. The life script a parent envisions for his/her child with a disability may complement or contradict the script that an agency or school has designed for that individual.Furthermore, the scripts operationalized in school settings and through adult service agencies are reflections of the directives set forth by professionals and policy planners, who are influenced by general culture models or *cultural schedules* of how the life course should proceed.

The evaluation of critical events is an adequate tool for interpreting some life histories. An evaluation of agency, parent, and personal scripts, and the cultural schedules that inform them provide an additional tool for understanding the life course of individuals with mental retardation. Through the framework of life scripts and cultural schedules, one can also view the intersection of individual aspirations, the influence of significant others,

and the historical and cultural circumstances that combine to determine the transition from school to adult life among other life transitions. Ethnographic methodology and participant observation also enabled us to develop convoy analysis, which can be used to predict the mediative capacity of individuals in transition. Overall, this type of analysis assigns meaning to statistics and outcomes that represent the success or failure of transition programs, but provides little guidance for the transition process. The result of the project is an argument for the use of ethnographic methodologies as a complement to the IEP process and a recommendation that future transition programs be modeled on mediation through mentorship.

Enhancing the Knowledge Base: Contributions of the Study

This research project has made a significant contribution to the knowledge base of research and practice related to the transition from school to adult life for persons with mental retardation using an ethnographic methodology (see Chadsey-Rusch, Rusch, & O'Reilly, 1991). The results of the project have both theoretical and practical implications.

Theoretical models and conceptualizations of transition (Halpern, 1985; Will, 1983) have directed research efforts towards studying the effectiveness of the transition process through the identification of *best practices*, that is, practices that could relate to predefined outcomes (e g., employment, independent living) (Stowitschek & Kelso, 1992). However, the identification of best practices has been problematic, partly because the perspectives of the individual with retardation and his or her significant other have not been incorporated into these research efforts along with the professionals' perspectives. With the use of an ethnographic methodology, we overcame this problem by conceptualizing the transition from school to adult life in the context of a life with mental retardation. Critical events identified

through life history interviewing, and the analysis of these events, provided the basis for an improved understanding of the transition period and planning of transition services. In addition, the method provided a uniqueness and personal perspective that outcomes of best practices planning do not. The project utilized a life course approach to go beyond critical events and, in doing so, led to the reconsideration of accepted models of transition. Future research may build on the results of this study to formulate models for improving transition services for individuals with retardation.

The practical implications of this research project are equally important. The need to document transition for the purposes of professionals working in transition-related matters has been identified. Personnel in a model transition project have indicated that an evaluation of model transition projects would benefit from a description along the lines of *The Cloak of Competence* (1993) by R.B. Edgerton (Stake, Denny & DeStefano, 1989). This research project documented transition along similar lines using an ethnographic methodology. In addition to its descriptive quality, this methodology may allow practitioners to work with individuals with retardation and persons in their social network in a way that may significantly contribute to the planning of transition services in the IEP meeting.

Research on transition has developed quite autonomously within special education, with little or no benefit from the study of life transitions in the social sciences, especially the literature known as *life course research*. The models of transition developed within special education have emphasized various aspects of the school-to-adult-life transition. The basic assumption of these models is that the transition process can be made more effective through the use of strategies or best practices (e.g., Rusch & DeStefano, 1989), and ultimately, that the process is predictable through the identification and manipulation of influencing factors.

These models of transition focus on outcomes, socialization into roles, and movement between environments with changing role expectations. Studies developing these models present transition from a service perspective; few studies investigate the process of transition from the perspective of the individual with a disability. In this project, an alternative perspective on transition is presented based on life history collection and life course analysis within the social sciences.

A major motivation for applying a life course analysis to the study of transition is the fact that the lives of and expectations for persons with mental retardation have changed significantly in recent years. Today, individuals with mental retardation have little experience with the pervasive negative and stigmatizing conditions that resulted from institutionalization, which was common until the 1960's. Persons in their early twenties with mild mental retardation will have graduated from ordinary high schools, and their futures as adults are partially built upon that experience. Consequently, a new approach, which accounts for the increased complexity that defines the experience of persons with disabilities as they transition through the various stages of life, is timely. A theoretical framework of the school-to-adult-life transition must combine an account of the individual's experience with an account of how that experience is historically and culturally determined; such a framework as the life course perspective makes a unique contribution to the literature on the transition from school to adult life for persons with disabilities. This theoretical framework provided a holistic backdrop against which many aspects of transition were highlighted in this study. Revisions to the framework, resulting from using a transition perspective on the life course, were expected and necessary. The application of an established methodology to new populations demands accommodations.

Methodology

One of the major goals of the research project was to pilot an ethnographic methodology that could be used to evaluate transition services and to enhance the effectiveness of IEP meetings and transition planning. The design of this project was characterized by (1) a limited number of research subjects, (2) a methodology that rendered information on the transition from school to adult life from the perspective of the individual with retardation (that is, an *insider's perspective*) (see Bogdan & Taylor, 1976, 1982; Zetlin & Turner, 1985), and (3) by a specific sequence of activities.

Including only 12 participants enabled the researchers to develop intensive collaborations with each of them, which resulted in multiple contacts in various settings. These contacts provided detailed information on the person's life and the transition from school to adult life. Intensive contacts were necessary for researchers to obtain insight into the direction of a person's life and to increase understanding of the critical events and particular directions. Such information could model future transition planning, because the collected information would be particularly relevant in this context.

An ethnographic methodology was utilized, consisting of life-history interviewing (e.g., Antonucci, 1986; Frank, 1984; Langness & Frank, 1981), the hierarchical mapping of social network (Antonucci, 1986), and participant observation with the individual with retardation (e.g., Edgerton, 1984). These research methodologies were complemented by interviewing others in the individual's social network and identifying critical events. Any comprehensive study of mental retardation must incorporate the perspective of the individual with retardation (Levine & Langness, 1986). In doing so, this project makes a unique

contribution to the literature, in which transition has been reflected for the most part from a service provider's or policy perspective (e.g., Rusch et al., 1992).

Sequence of Activities

The project was executed in several phases. An initial preparatory phase included development of agency agreements, identification of individuals, and initiation of a research relation with individuals. Time was spent with the individuals prior to data collection in order to establish the rapport necessary for any good researcher-interviewee relationship.

The second phase of the project consisted of several types of data collection including life history collection, mapping of the social network, and data collection from the IEPs of the research participants. The third phase related to the analysis of these data. From a theoretical perspective, the focus was on the description of the nature of significant events in the lives of persons with mental retardation and the direction that their lives took as a result of the occurrence of these events. From a practical perspective, the focus was to determine how the collection of these data could contribute to the participation of the individual with retardation and significant others in the planning of transition services. The collection of these data will help professionals in their assessment of a person's life and will be instructive for their planning as members of an IEP-team.

Sample

Twelve individuals were interviewed as participants in this project and as members in their social network. The possibility for attrition during the course of the research made it necessary to oversample. To provide a variety of life histories, male and female, individuals from rural and urban areas, and experiences of persons at different stages in the school-to-adult-life transition were included. The researchers were sensitive to the impact of

socioeconomic and ethnic background, but these were not used as initial sampling criteria. The purpose of the sampling procedures was not to represent the population of persons with mental retardation, but to work with as diverse a sample as possible given the limitations of sample size. This diversity was instructive for depicting the multiple directions taken by lives of these with mental retardation.

Instrumentation

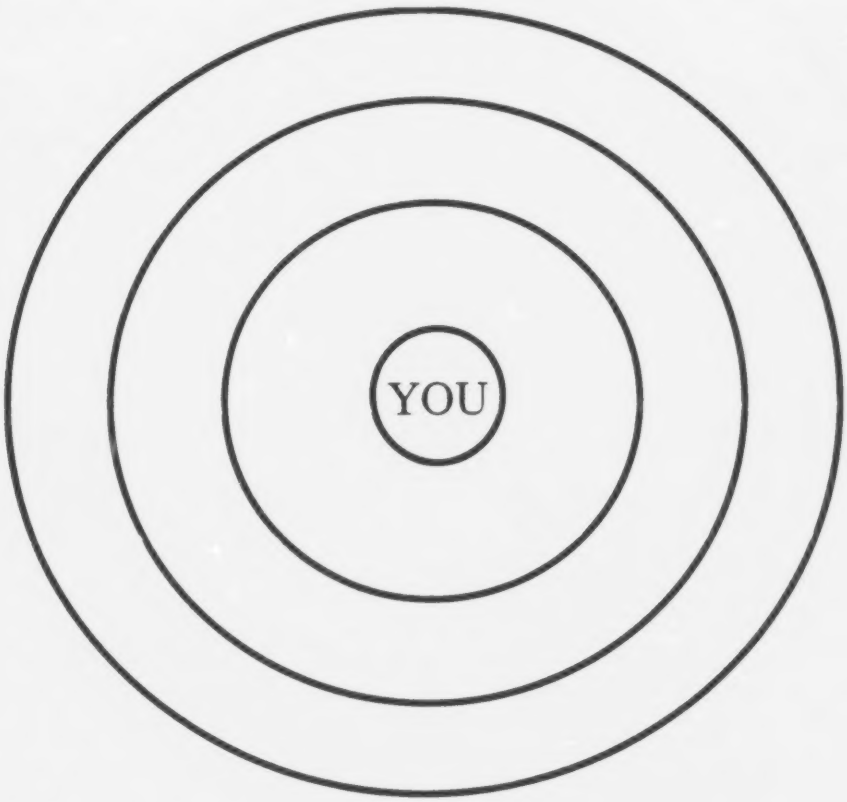
Life-history interviewing was conducted using an interview schedule covering a number of areas in the person's life. The life history interview was usually carried out over a minimum of four sessions with the individual with retardation. In the first session, interviewers assessed the living situation, employment, recreation, and daily activities of the individual with retardation. During the second session, the individual was asked about important events and the impact of people in his/her life. The social network diagram was used during this session (see Figure 1.1). The third session involved questions focussed on the transition from school to adult life. In the fourth session, the researchers asked the individual to analyze and integrate events in a personal perspective on his/her life path.

Once significant events in the person's life were identified, significant others, who were identified with the social network diagram (Antonucci, 1986), were asked to portray their perspective on the individual's life history. Such a procedure ensured a complete and detailed narrative of events and provided some verification of the accurateness of the information. The triangulation of sources not only ensures accuracy, but also provides an opportunity for some discrepency analysis.

The social network diagram and the technique of hierarchical mapping enabled the respondent to map members of the social network hierarchically according to three levels of

Figure 1.1

Social Network Diagram (Antonucci, 1986)



emotional closeness by enumerating persons in the social network and placing them in three different circles according to emotional closeness. Once these individuals were categorized, researchers inquired about the relationship between the current situation of the individual and the impact of persons who were emotionally close.

In order to collect information from the IEP reports, researchers used a protocol that included the composition of the IEP team and content areas of transition planning as stipulated in the Individuals with Disabilities Education Act of 1990.

Data Analysis Procedures

Data analysis procedures focussed on the nature of the data to be collected and ensuring the validity and reliability of the data sets. Three types of data were collected in this research project: (a) data related to significant events, (b) data on the social network of the individual with retardation, and (c) data from the Individual Education Plans.

Data Related to Significant Events. Significant events were identified as they were narrated in the life-history interview by the individual with retardation. Interview data were analyzed by identifying significant events in the life-course and in the transition from school to adult life, resulting in event charts. Then significant events from one period in life were related to the transition from school to adult life, based on interpretation of the individual with retardation and persons in his/her social network.

Data Related to the Mapping of the Social Network. The social network diagram was piloted with several persons with mild mental retardation to obtain a satisfactory set of procedures. When these procedures were established, that lead to a hierarchical mapping of the social network on the basis of emotional closeness. The data obtained from this instrument served as the basis for choosing individuals to be

interviewed and to contribute information that complemented an insider's perspective to transition. One basic assumption was that persons who are not perceived by the individual with mental retardation as emotionally close are less likely to provide information that contributes to an insider's perspective. Because the primary goal of this research project was to portray an insider's perspective, we felt that working with individuals who were emotionally close to the individual with retardation would complement such a perspective.

Data Related to the Individual Education Plan Meetings. The information collected from reports of the Individualized Education Plan meeting represented more of a service provider's than an insider's perspective. First, we analyzed the composition of these meetings. It was assumed that the presence of the individual with retardation and significant others influences the dynamics of this meeting and that the presence of a school counselor or a representative from an adult services agency were likely to influence the effectiveness of the transition planning. Second, the content of the IEP plan as it pertains to transition was analyzed for the presence of outcomes that reflected such factors as postsecondary education, continuing and adult education, community participation, adult services, vocational training, independent living, and integrated employment. These areas have been defined as goals for transition planning in the Individuals with Disabilities Education Act of 1990. An assessment of the transition planning was important to provide a perspective on the collection of additional data (e.g., on significant events in the person's life), as it is proposed in this research project.

Reliability and Validity of Data

The same questions were asked on different occasions to address commonly observed problems in open-ended questions, such as underreporting. Repeated questioning also increased the reliability of data, as did the repeated presentation of the social diagram. Furthermore, the completeness and accuracy of the data were addressed through two ways of triangulation. One triangulation was based on sources of reports, as both individuals with retardation and significant others were interviewed. The other is triangulation focused on methods of data collection. Although life history interviewing was a major methodology in this research project, the unobtrusive observation of participants and occasional conversations complemented the information obtained in more formal interviewing.

Practical Applications

This monograph examines both the theoretical and applied impact of this research project on transition planning. Chapter II discusses existing models of transition and presents alternative perspectives to transition gained from incorporating life-course analysis. In Chapter III, a transition services approach based on mentorship and mediation is proposed. The proposed alternative model is significant because it defines transition within the lifespan of an individual and strongly relates to the social network of an individual. Specific recommendations will be made that may enhance the independence of the individual with mental retardation and the empowerment needed. Analytical techniques essential to life course analysis, such as life history collection, critical event analysis, script analysis, and convoy analysis, are described and applied toward understanding the transition of individuals with mental retardation. Chapter IV includes

the life histories of seven individuals who constituted the data base for this research. The life histories of those persons in transition are presented first, followed by those of individuals who are preparing to transition and who went through transition several years ago.

The monograph takes a look beyond school outcomes to expected outcomes and processes in later life. Building a long-term perspective of transition practices will significantly improve current practices and benefit future students. The discussions included in the following chapters will enhance understanding of the influence of the natural support system of the individual with mental retardation as well as its programmatic implications.

The expected results of this project are significant. From a theoretical perspective, the research project will increase understanding of the relation between critical life events and events in the school-to-adult-life transition. In turn, life history material will be useful for training professionals or advocates who may participate in the preparation of IEP meetings. The description of a methodology that may be applied in transition research and service development could serve as a vehicle to collect another dimension of information for planning and include the consumer in that planning. Training professionals and advocates in the collection and analysis of critical events information will facilitate the use of life history materials.

CHAPTER II

MENTORSHIP FOR TRANSITION

Effective mentorship skills such as (1) life history information collection, (2) adult script and social network analysis, (3) assessment of mediative capacity, (4) problemsolving, and (5) technical career planning are all part of a comprehensive model of mentorship for transition. Professionals concerned with current transition planning should already have the skills of problem-solving and technical career planning. This project contributes to the development of life history information collection and adult-script and social-network analysis. These skills are presented to assess effectively the mediative capacity of the individual and his/her social network in the transition to adult life. For example, if it is determined that the individual has the skills and resources to mediate the transition effectively, then problemsolving and technical career planning will be less important mentorship skills. Where mediative capacity is found to be insufficient, the mentor will need problemsolving skills. The Individual Education Planning process should be a good tool for problemsolving with persons with disabilities, and their social networks should be redesigned to concentrate on these activities. Consequently, if this approach proves to be more effective, it should be reflected in future policy that addresses the reform of the IEP process.

Mediation and Mediative Action for Transition

This research defines *transition* in the context of the life course as "a flow of significant events that precipitates personal mediation and is marked by physical changes and social realignment." Mediation is the ability to reach out in the world, to make things happen.

Its process is often one of negotiation between two or more parties which often do not represent one person, but a network of individuals. The current discussion about self-determination and empowerment overshadows the fact that individuals act not only on their own behalf, but on behalf of themselves as part of a group of close consociates. Mediation is often facilitated by a mentor who can act as go-between. In some cases, it is the only way of reaching out. Persons with disabilities can often mediate part of their own situation and should be encouraged to do so. In all situations, how a transition concretely occurs is the outcome of a negotiation in which both the person with a disability and his/her social network play a role, be it positive or negative.

Methods

Life History

Life history is a well-known method within anthropology that essentially is intended to reveal the complexities of a person's life in its sociocultural context. Life histories must be distinguished from case studies, which are more limited in scope and usually are designed to gather information for specific purposes. Life histories are holistic in that all dimensions of life are considered. For mentorship to occur, an attitude of interest in the whole person is necessary before action is directed toward specific goals. As students participate in educational programs, the conditions are there for them to develop relationships that can lead to mentorship. However, in many cases the educational context may limit the scope of attention because of specific goal-oriented activities. Because of the richness in information, life history methodology exceeds the usual professional standards. This is necessary because mentorship can only succeed when persons bring out the best of themselves, as professionals and as human beings. In essence, the life history method formalizes some of the very natural

behavior and knowledge development that emerges as people develop relationships. A practical model will be presented in which both technical and ethical issues are discussed.

Technical Issues

Of primary importance in the development of life history material is asking the questions that start with the person's current situation. Only when this information about the current situation is well developed can the interviewer move back and forth in time. The interviews are best conducted over at least four sessions that build information on the present situation, before moving back or forth in time. Notes on the interview can be taken in anecdotal format, immediately after the interview has been conducted. For research purposes, interview sessions should be tape-recorded and transcribed. It is important for the interviewer to form a mental picture of the issues that need to be addressed during the interview and what needs to be accomplished. The following provides a description of the four sessions.

First Session: Assessing the Current Situation. The first session is designed to develop a composite picture of the life of the person with a disability, covering topics such as living conditions employment, friends, recreation, education, and a description of the usual daily routine.

Second Session: Historical and Social Components. Based on the information collected during the first session, this session moves more widely, placing the situation of the person in both the historical and social contexts of the person's current life course. In the historical context, it is important to know what the significant events were in the person's life. A good entry point is to ask about the different moves the persons has made since childhood and to inquire about events that had a strong influence on the person. The social context of the person can be investigated with the use of Antonucci's social network diagram -

(Antonucci, 1986), in which the person is asked to list persons in the social network that are important, but have various degrees of being emotionally close. The person is asked to sort out persons in the social network that are very close, less close, and least close. The interviewer should check accuracy by reviewing the individuals that have been enumerated during interviews. If the person with a disability does not list certain persons, the interviewer may check to see whether this person should be listed and where. From the social network diagram, a composite picture is developed of the social landscape in which the person with a disability moves.

Third Session: Transition to Adult Life. Where the second session widened the information of the first, the third session focusses on the particular issues related to transitioning into adult life. However, this session should be based on the information collected in the first and second sessions. Reviewing the abstracted notes that were taken at these sessions may be very helpful. In this session, the issues related to transition must be addressed, such as living situation and employment and social support during the transition. It is important to think of the transition to adult life first as a transition that occurs in the context of a whole life rather as a technical process to be carried out from the perspective of the school or the legislation, and second, as a normative transition in American culture, that is, one that occurs for all.

Fourth Session: Assessing Mediative Capacity. The purpose of the fourth session is to assess the strength of the person's mediative capacity, which consists of reflecting on important events in life, evaluating their purpose, projecting future life, and taking appropriate action. In collecting information, a mentor must assess the extent to which the person can take the initiative and negotiate the world beyond high school, and assess the

strength of the support structure. From insights gained in this session, mentors may decide that the person with a disability and his/her social network have the capacity to mediate, and that the role of the school should be limited to providing assistance when required. Likewise, limited mediative capacity may urge the mentor to contribute more of his/her own or others' mediative capacity. In this context, the Individual Education Plan can be used for problemsolving. The long-term objective of problemsolving is to increase the mediative capacity of those directly involved in the transition process. In order for problemsolving to be effective, the outcome must be an assignment of specific responsibilities.

Convoy Analysis

Analyzing the convoy of the person with a disability is a skill that mentors of transition should master. It is important to assess the structure of the convoy because life transition does not occur in a social vacuum, but in cooperation with real people; the life course may be thought of as the journey of a school of fish or a convoy of ships. Consequently, at critical times in the journey, the group realigns; significant members become less significant, while others join the group and gain significance. During the life course, some members maintain more significance as close consociates than others. Professionals who view their transition-aged students with disabilities as persons on a life journey need the skills to assess the student's social network. While the interview sessions will provide information about the student's social network, it may be useful to have a more structured picture of that social network and to assess the quality of support provided. The following section describes both the collection of structure material about the social network and the range of analytical description of the quality of the social network.

Antonucci's social network diagram is a useful tool to use in picturing the social network of the person with a disability. The diagram consists of three concentric circles in which persons in the social network with different degrees of emotional closeness are outlined (see Figure 1.1, p. 10). The instrument structures the support according to emotional closeness and provides insight about the nature of support an individual could expect. However the static nature is a drawback. A completed diagram gives a picture of the current state of one's social network, but does not provide insight about the possible development of the network. The interview sessions play a critical role in providing this information. Therefore, the social network diagram is best used in conjunction with the interview sessions. With the information from the interview sessions as a background, a mentor may easily detect flaws in the accuracy of the social network reporting. For example, some persons mentioned in the interviews may be overlooked, or some persons may not be placed correctly in the most appropriate category of emotional closeness. With these checks in place, the social network diagram will provide useful information about the mediative capacity of the person's social network. If the mediative capacity is undeveloped, the social network diagram could be used as a basis for problemsolving within the context of an IEP meeting.

Critical Event and Life Domain Analysis

Critical event analysis identifies a single event, or a limited number of events, that may be of great significance in a person's life course. It is especially important to single out these events from the interview sessions and to evaluate their importance in light of the transition to adult life. These events may be useful in mediating the transition process.

The transition to adult life in the context of American culture is one of growth toward more independence and self-reliance. Life domain analysis evaluates the growth in the

different areas of living. Wehman (1992) has described five life domains that affect outcomes of the transition beyond high school: work, independent living, self/sexuality, peer relations, and independent mobility. From this study of twelve persons, it appeared that the domains of work, independent living, and independent mobility are less problematic than self/sexuality and peer relations, probably because public domains of becoming independent find more systematic support than the private ones. The interview sessions indicate the areas in which the person lacks sufficient growth. The objective should be to make an informed decision. It is important and reassuring for mentors to discuss their assessments with other professionals, with the person with a disability, and with other persons in the social network. If some areas are highly insufficient, this finding could be a basis for increased skill development and problemsolving.

Event and domain analysis are important in obtaining a picture of the individual dimension of a transition-aged person, but these levels of analysis are static and do not reflect the dynamics of a life transition. However, conceptualizing a transition script provides a remedy for these flaws.

Script Analysis

A script is a dynamic, composite picture of the transition to adult life of a person. The description of a script incorporates the quality of the transition process within a flow of events of a particular person and describes the markers of the transition. The description of the flow of events can best be described while answering four different questions, related to (1) socialization in an adult agency; (2) relation between past and present; (3) parent responsibility; and (4) individual negotiation of life domains. The answers to these questions

may be further summarized in one composite descriptive term that summarizes the script. Examples of different scripts can be found in Table 3.3.

Socialization with an Adult Service Agency. As the responsibility of one social institution, school, comes to an end, entering an alternative social institution such as an adult service agency may be a very complicated process. In essence, the socialization with such an agency may be nil in the case of persons identified as having no need to receive adult services. On the other hand, it may be extreme in the case of a person for which a total immersion through living and working within an adult agency is preferred. There are numerous possibilities between these extremes. In short, the question that needs to be answered is: How strongly will the person be socialized in an adult service agency?

Past and Present. Transition from school to adult life can be a smooth process that is slowly built prior to graduation from high school. On the other hand, persons with disabilities can find themselves confronted with major changes in their lives at the time of their graduation. In a matter of a few weeks, they can move from their parent's home into a group home and start working in a sheltered workshop, sometimes without much support from their parents. In such a case, the script can be described in terms of strong disjunction with past experiences.

Release of Parent Responsibility. From the perspective of parents, the transition from school to adult life has been described as a series of "letting-go's" (Turnbull et al., 1983). The emerging adult script of a person with a disability will be strongly influenced by his/her parents' release or protection of their responsibilities.

Individual Negotiation. Within any given situation, the individual's initiative in daily activities and input in the direction of greater independence in selected life domains are

important indicators of the transition process. In negotiating their lives, some persons with disabilities do not take, or are not allowed to take, any initiative. A strict script is imposed on them. At the other extreme, some persons take the major share of responsibility and decision making, and are the sole drive toward greater independence.

While a script can be described briefly in terms of four criteria, the transition process can be further described with an indication of the physical and social markers of the transition. Physical markers indicate the moving from one living environment to another. Social markers indicate the realignment of one set of persons to another set of persons that are part of the social network of a person with a disability.

Examples of Emerging Adult Scripts. Table 3.3 describes examples of different types of adult scripts and accompanying transition markers. Such analytical descriptions are very informative of the activities that schools and adult agencies may initiate to further facilitate the transition to adult life.

CHAPTER III

FROM "TRANSITION" TO "LIFE TRANSITION"

History and Development

When the Individual Education Plan process was developed in response to the passage of P.L. 42-142, the Congress intended that parents and schools could use it as a contract for the educational program that a special education student was entitled to receive. The intention of the Congress has been overshadowed as the IEP has become a device that guides instruction (Goodman & Bond, 1993).

The IEP has also become the means for the educational organization of transition planning, which arose from the federal mandate for transition services. On the basis of this study, several issues must be addressed. First, the federal mandate for transition services has further complicated the original purpose of the IEP by making the IEP the centerpiece for educational planning. Within this extension, transition services are dealt with as if these concerns are the primary responsibility of education, as the supporting institution. In this project, transition is interpreted not as an essentially educational matter, but rather as a fact of life. Second, whereas transition is perceived as a process that involves other support systems in addition to education, the IEP, based on teamwork, is often seen as the basic mechanism of transition. It has already been determined that the student with a disability may be marginalized within the mechanism of teamwork. However, the mechanism of teamwork itself has not been questioned. Instead, efforts have been mounted to increase the self-determination of students so that they can speak for themselves.

The purpose of this project is to reflect on the basic mechanisms of life transitions as a starting point for redesigning the IEP, so that it can facilitate a life transition. At the outset, it must be recognized that the role of the IEP will be limited, because its team problemsolving method is limited in mediating life transitions. Instead, a comprehensive mentorship relationship is proposed in which a team-oriented, problemsolving activity, through the IEP process, could have a place.

Teams and Transition Outcomes

Current IEP practice is highly inadequate for transition purposes. The presence of students, school counselors, rehabilitation counselors, and parents at IEP meetings, and the development of transition goals and outcomes in IEP plans as stipulated in the Individuals with Disabilities Education Act of 1990 (P.L. 101-476) is highly inadequate (Trach, in press). This research indicates the limitation of the IEP and raises questions about the IEP as the most effective vehicle for planning the transition from school to adult life.

One of the limitations of the IEP is its reliance on the team concept. Although teams are effective in problemsolving, they do not offer the most effective approach for helping an individual make a transition in life from one situation to another. A team approach may even be counterproductive in accomplishing an effective transition because of the timeliness of decisions to be made and the division of responsibility for decisions amongst team members. It needs to be noted that, in this monograph, comments about the IEP process refer only to its application in providing transitions services. Where problemsolving is a necessary part of the transition process, the IEP should maintain a critical function.

Understanding Life Transitions

One goal of this project has been to understand the transition from school to adult life within the context of the continuum of life, as one transition in a series of life transitions. The transition literature, especially the early studies, indicated an interest in some broader context for studying the transition from school to adult life, such as transition as part of the complete life span.

This report complements the existing transition literature in two important ways. First, transition to adult life is interpreted in the broader context of life. Using the life course approach, it is critical to go beyond the individual characteristics and to incorporate other dimensions that characterize the transition by developing a methodology for situating transition within the context of the entire life span; the ethnographic life history is perhaps the best available methodology to achieve this goal. Life histories portray complex phenomena about persons, including life transitions. Despite the diversity and complexity of life transitions, the central issue in this inquiry is not to present a comprehensive account of different transition issues as they are represented in the lives of the persons in this study. Rather, the objective is to learn about a particular phenomenon, a life transition at a certain time in life--the critical event is leaving school--and is lived by people who belong to a recognized special population. In examining the phenomenon of life transition, we focus on the fundamental structure and its specific qualities as well as the impact of mental retardation on this human process of transition.

The life history has been used to describe the lives of persons with mental retardation by Edgerton and his sociobehavioral group, who consider the content of what people say as central to the coherency of their lives and who document the changes and process in the lives

of persons with mental retardation (Edgerton, 1984). Attention to process is also emphasized in the present study. In defining life transitions, a holistic picture of the lives of persons with mental retardation is drawn in which process is an integral part. Angrosino (1994, p.24) also relies on the work of Edgerton and associates, but he is more concerned with "the way in which an entire life was reconstructed in the narration around a master concept of self." Here too, the concern is with developing a holistic picture of the transition of the person's life, but the focus is narrowed to the person's transition to adult life as the emergence of a script. However, here such a script is not centered around self but around the outcome of a concrete negotiation between self and significant others who are involved in the process of transition. From Bogdan and Taylor (1994) the importance of an insider's perspective is retained. The importance of the insider's perspective has influenced designing the collection of materials, in which the person's own perspective is favored. However, telling the story of a life is not the primary interest. More than the work in the area of life history research with persons with mental retardation, this project is influenced by recent developments in qualitative research, especially the issue of "voice" (Sparkes, 1994) and the "goodness" of qualitative research (Peshkin, 1993). Although the issue of voice is important in view of the marginalized position of persons with mental retardation, it is not our primary intention to enhance the voice of persons with mental retardation. This is, however, a possible outcome. It is perhaps even more important to consider the "goodness" of describing processes and people and in the act of interpretation that may clarify the complexity of life transitions.

The life history approach used here is topical and strategic. The life histories presented in this monograph are topical because they focus on a portion of the persons' lives, the transition from school to adult life (see Denzin, 1978, p. 218). They are "strategic"

because life histories can only represent a fraction of the diversity of life events that structure the lives of people with mild mental retardation in American society. The events depicted were chosen because they help to clarify the phenomenon of life transition to adult life as a process.

The people portrayed here include both men and women who live in urban and rural environments, and in a variety of settings such as the group home, supervised apartment, and the parents' home. They also work in a variety of settings, including a sheltered workshop and a private company. One person was unemployed. Beyond these criteria, the individuals represent unique sets of problems and situations. Life histories, as a research method, can be sensitive to this uniqueness because the researcher is allowed a flexibility of data collection and presentation.

This section presents one life history, that of Tina, which was chosen for the amount of insight that it revealed. Better than most, Tina's life history helped to explain the basic structure of life transition and to situate the transition to adult life in the context of a whole life. The intellectual benefits from studying Tina's life history could be best captured in a traditional narrative style. By incorporating direct quotations, aspects of Tina's mental limitations have also been conveyed.

The life histories of seven other individuals are presented in the final part of this monograph. Without distorting any of the facts in their lives, the life histories are presented in different formats so that we could discuss some of the dominant issues in the transition from school to adult life using a limited theoretical framework. When this research was initiated, lives were conceptualized from the critical events which give or change direction to one's life. However, representing lives in terms of critical events was soon found too limiting as an

overall strategy. Although some lives are eventful, such as Tina's life, and can be told in terms of consecutive events that direct one's life and give consistent meaning in an overall context, the lives of other persons are characterized more by the absence of critical events. Their life courses are characterized by shifting relationships and physical spaces that also dominate their transition from school to adult life.

The persons in the study are not a homogeneous group; several criteria were used, such as gender, current living situation (rural, urban and metropolitan areas), current school status, and persons who are fewer than 10 years out of school. The contacts who identified the persons with mental retardation were also from different backgrounds: a director of residential services in an urban agency identified six persons, a vocational coordinator in a rural agency identified two persons, a school vocational coordinator in a rural school identified two persons, and two personal friends helped each in identifying one person. Both the selection criteria and the background of the persons who helped to identify participants account for the diversity of the subjects.

Using life history, it was assumed that one can learn about transition from each life history. What one can learn, however, differs with each person, both in quality and quantity. In the final part of this monograph the sequence of the life histories is constructed so that one may learn in a logical way. With the presentation of the life histories, an exploration is initiated that can be refined each time another person's transition to adult life is studied in-depth. Persons who would like to assume roles as mentors-mediators in the lives of persons from special populations will find this a useful start to increasing their knowledge and making the development of such knowledge more conscious.

Tina: A Success Story

Tina was born in 1970 in the South, where she lived with her mother, father, and sister. This early part of her life changed abruptly at the age of 11 months when she was taken to the hospital with a broken arm, after which she did not join her family again. An entry in her file notes that she has arthritis in her left shoulder as the result of abuse as an infant. Thinking about this part of her life, Tina says:

> *Well, I do got a real Mom somewhere, but I don't get to see her or I don't see my Dad. The only time I see my Dad is [when] I go down South, or [when] I'll see my grandma, or [when] I'm with my sister. That's the only time I see my Dad. The reason they couldn't keep me is because they were being mean to me. When I was a little kid, when I was a baby, they'd throw me to the wall and mess my arm up.*

Friends of both her biological parents and prospective parent arranged for her adoption. At the time of Tina's entry in her new family, the adoptive mother, Erna, had just gone through a divorce while Becky, her adoptive sister, had just graduated from high school. When asked about the connection between her mother's divorce and Tina's entry in the family, Becky said, "*I think it was Mom's life line. Mom loves children and Tina was there to kind of fill a void in some ways. Tina did just fine. We had a normal home life. She was raised in a one-parent family like one of us kids except I spoiled her.*"

When Tina was about 10 years old, Erna was diagnosed with cancer which, according to Becky, *"was kind of rough on Tina."* Erna knew that she was terminally ill and as a result, Becky had moved back home to care for her mother. Before Erna passed away, she arranged for Becky to be Tina's legal guardian. They continued to live in the mother's trailer until Becky got married. Tina was about 16 years old at that time.

Both Becky and Tina moved into the husband's trailer which was "newer and larger." Since then, the new family moved several times. Each of these moves related to the education and employment of Jeff, Becky's husband.

For both Becky and Tina, several life transitions occurred simultaneously. Adapting to new roles in marriage, Becky faced significant difficulties. The history of her family-in-law was tragic--several members of her husband's family had been killed by an ex-boyfriend of the husband's sister--which strongly affected Becky's relationship with her mother-in-law. Moreover, the marriage suffered, and she and her husband fought frequently.

Transitioning into Adult Life. Tina's transition to adult life had specific characteristics as a result of intersecting with the life transitions of both her brother-in-law and her adoptive sister, as well as her enrollment into special education programs related to her mild mental retardation. Becky's marriage led Tina to adapt to a different home and living situation. One report in Tina's agency file read that an agency person had contacted her adoptive sister who had reported, *"Tina had adjusted well to her marriage and the move and that Tina relates well to her sister and brother-in-law. Sometimes she does show jealousy of time spent with her husband. However, she respects the husband and interacts well with him."* Probably, more significant for Tina's adjustment were the ensuing marital problems which forced Tina to choose the side of her adoptive sister against the brother-in-law, especially when situations became violent. Her relationship with Jeff deteriorated from such incidents. When interviewed just before Christmas, 1993, Tina had just been informed by Becky of new marital problems, and was upset by the situation. This made Tina decide, perhaps as the result of counseling with her apartment supervisor, not to spend the holidays with them in order to avoid confrontation.

The physical transitions that were connected to the education and career of her brother-in-law directly resulted in Tina moving from one school to another. Tina found it hard to leave the special education program that Erna had arranged for her. In some of the new schools, special education programs were not available.

During the last year of school, Tina's special education program organized a work program for her to clean rooms in a motel. She detested the job because she felt that her supervisors and other individuals at work were difficult to get along with. About one supervisor, Tina said,

> *If you miss one spot, she makes you go over it. Sometimes, she got me mad, she was not happy of what I did. I just forgot the Kleenex in there or I forgot to shut the window and turn the heat on. Because in the wintertime, I open the window when I'm in there to clean because it's hot when you're sweating and you're trying to dust and make the beds. That's the part I hate. And sometimes they time you to see how fast you could get done in one room.*

About one of the individuals also working at the motel, she mentioned:

> *And then we had this other guy [who] is crazy, he's stupid. And I didn't like him because he was a weirdo. He would come around and pick on me or he'll steal my money when I got a tip. He'll take it and he'll take it down the hallway and I'll say "give it back to me, or I'll hit you." And he'd bring it back. Because he knows I was gonna hit him.*

The marital problems, involvement in special education, and Tina's nearing graduation from high school compelled Becky to contact a service agency that is involved in residential and employment services for persons with mental retardation. This resulted in a new turning in Tina's life. Becky, an agency person, and friends of her sister helped her to

move into an apartment in a building that belongs to the agency and that houses people with mental retardation. On the first visit with Tina there, one research associate noted that, *"Tina's apartment was very homey with nice furniture (a matching set), Christmas decorations, trophies from bowling and swimming and stuffed animals everywhere. Everything was very neat and clean, yet it looked very lived in."* Tina's interpretation of the reason for her move to the apartment was her deteriorating relationship with her brother-in-law. The service agency person interpreted the move more as a victory, an act of independent living. Becky, from her perspective, welcomed the move and stressed Tina's need for independence but also her need for guidance and Becky's own role as a guardian. She said,

> *Tina is her own guardian in some respects, but I still have power of attorney over her business and over her medical. Tina does a real good job over everything, but she does need a little guidance and a little understanding. She really enjoys her independence and I'm glad for her. We all need to spread our wings and grow. She's done real good for everything she's had tossed against her, so... more power to her.*

The service agency arranged a job for Tina at a large retail store and trained her to take the bus from the apartment to work. Tina acknowledges,

> *The person to get me the job is Janny. Because they would want to put me in the post-office, and I say "aha, I would not know which one to go there." I told [them] I did not want the post-office because it would be too hard to do, putting mail in the right place and everything, and then you got to go out and take it to the mailbox. Nooooo! I can't do that, because I won't know where the street is. And then they say no, they found me a real nice store. And I got more friends there.*

Tina works in the back of the store. Her job is to hang clothes on hangers, make up tickets, change the prices, and clean up trash. She works directly with Andrea, an older woman, who helps her when necessary. From Tina's account, her service agency person who supervises her work really works with Andrea,

> *Janny will come in and check on me and see how I'm doing with my job. Sometimes she'll go over and talk to Andrea about my job, how I'm doing, if I'm doing OK, and all that. Andrea will tell her I'm doing a fine job and all that. They always say stuff nice to me back.*

Tina's file indicates that both the store and the agency must have been pleased with her work. The store acknowledged her as "employee of the month" and an agency person noted that *"she has been doing extraordinary work by herself according to her [store] supervisor. Hanging clothes has been maintained at an acceptable rate."* However, Tina said that she was often worried because she felt that she *"could not get all of the hanging done each day because she was the only one working."* At any rate, Tina's association with a service agency, which resulted in independent living and working, is interpreted by Tina, agency workers, and even Becky, as being a success.

Perhaps some of the more personally significant events in Tina's life are the new relationships she has developed since moving into her apartment. Tina has a large network of friends, some very close and others more distant that evolved from contacts at the apartment and at work. Interviews were usually interrupted every 15-20 minutes by a telephone call or someone dropping by her apartment. Most significant, however, is her relationship with her boyfriend, Jack, who is also a client of the same service agency. Both have been talking about

marriage. They do not wish to have children; and an entry in Tina's file notes, "Tubes tied," dated July 1993. Her boyfriend became a model for evaluating her guardianship relationship with her sister. Tina says, *"I want to be on my own with guardianship. Just like Jack. He's only himself guardianship. It's not his parents or anything else."* However, she realizes that marriage may be the condition for her to become fully independent from her sister. From her sister's perspective, Tina's relationship with her boyfriend is problematic. Becky did not like Jack when she first met him. She also distrusts him because *"he goes off chasing other girls, and when that gets old he comes back to Tina, and he and other people talked her into spending money she didn't need to spend."* She tries to avoid the subject with Tina because they disagree on it. She tries to refrain from forbidding Tina to see him because she realizes that *"it's like any kid, you forbid them from seeing someone they like and they're going to turn around and do it anyhow. So, fine, Tina, go ahead and see him."* Although she wishes that Tina could enjoy her freedom more and say goodbye to Jack, she realizes that she has little control over it. She is concerned however that Tina cannot easily say no, and that she is too easily persuaded.

When Julie, the agency person, was asked about Tina's social relationships, she framed it in the context of social skills and acknowledged that

> *Although Tina is rather shy and quiet, she has evolved a lot in that area, with developing friendships inside and outside the apartment, and learning who to trust and not to trust. A lot of that is not anything we even set up for her or provided for her. Sometimes we try to do that if we feel that people are feeling lonely and having a difficult time meeting people.*

On the topic of the relationship with her boyfriend, the agency person left things open but added a perspective on the boyfriend as she knew him longer.

> *He's kind of always wanted a long lasting, serious, mature relationship. I don't know if theirs is mature or not. I think they're both growing together and learning about those kind of relationships together. I think that as they will become more emotionally mature things could evolve. Who knows, they might learn as they're growing that they don't want to be with each other, but I think that the capacity is there.*

Ethnographic Notes. Interviews with Tina were conducted between November 1993 and January 1994, and visits with her continued in the fall of 1994. She was living in an apartment, managed and supervised by her service agency, and was working in a large retail store, also assisted by her service agency. Tina became part of the research project after her service agency had obtained her consent to participate and her apartment manager volunteered to introduce her to research staff. After the initial introduction, she agreed to meet several times in her apartment to talk. By the second meeting, her boyfriend Jeff joined the discussions. After one interview, the group went out to have dinner at a nearby fast-food restaurant. These meetings were complemented with one interview with an agency person, whom Tina identified as someone that knew her well and with one interview with Becky, her adoptive sister. The information from the three individuals during these meetings aided the reconstruction of Tina's life history.

Theoretical Interpretations. On the assumption that life histories are "good to think with" in the theoretical context of the life course, the process of studying transition by looking at individual and social dimensions of life transitions has been explored. In

organizing Tina's life history, the different residences where Tina has lived as well as all the significant events are the main instruments for organizing the material. Table 3.1 accompanies Tina's life history. A life transition should be understood as the macro level indicating a major change or turning as the result of a shift from one period to another. It is to be distinguished from the more subtle changes a person experiences on a daily basis.

In Tina's life history, the changes of residence are meaningful indicators. A life transition is preceded by significant events that lead up to the transition. "Being thrown to the wall" is an example of an incident that led to Tina's first life transition, isolation from her family and her adoption into a new family. However, a significant event may not be sufficient cause for a life transition: for the adoption to happen effectively, the mediation of friends was necessary. In all of Tina's life transitions, mediation is indicated in the Table 3.1. For example, Becky's boyfriend could be interpreted as the mediator of her life period in the residence of her adoptive mother. A significant realignment of consociates that marks the beginning of a new life period is the result of more or less extended mediation. Life transitions become intersected, that is, the transitions of one individual become dependent upon the transition of others. The complexity of Tina's life history makes this overwhelmingly clear. Her life transitions have been significantly connected with those of her mother, her adoptive mother, her adoptive sister, her brother-in-law, and may now become interconnected with those of her boyfriend. It appears that a life transition is preceded by significant events, characterized by residential changes and realignment of consociates, resulting from intended mediation, and intersected with the life transitions of consociates. From these insights, the following definition of a life transition is proposed:

Table 3.1

Tina's Transition to Adult Life in the Context of a Life-Journey

1. **Parents' Home** **(0-11 months old)**	2. **Adoptive Parent's Home** **(11 months-15 yrs old)**	3. **Adoptive Sister's Husband's Home** **(15-21 yrs old)**	4. **Agency Apartment** **(21 yrs-present)**
Alignment Mother/Father/Sister	*Realignment* Erna/3 biological children/Tina	*Realignment* Jeff/Becky/Tina	*Realignment* Patty/friends/boyfriend
	Intersected transitions 1. Erna	*Intersected transitions* 1. Jeff	*Intersected transitions* 1. Tina
Critical event Child abuse	*Critical events* DIVORCE: social void Tina's entry in the family CANCER: social void Guardianship relation DEATH: social void Becky and Tina continue living together in mother's trailer	*Critical events* MARRIAGE: both Becky and Tina move in STUDY: physical move WORK: physical move	*Critical events* MOVING: new consociates WORK: new consociates
Social void Hospital	2. Becky	2. Becky *Critical Events* MARRIAGE: marital problems MOTHER: confinement to home	
	Critical event ENGAGEMENT	3. Tina *Critical events* MOVE TO NEW SCHOOLS CAUGHT IN-BETWEEN MARITAL FIGHTS TRANSITION SCHOOL TO WORK	
Mediator Friends of both families	*Mediator* Becky's friend	*Mediator* Agency worker and Becky's friends	
Period lingering on Visits to father		*Period lingering on* Visits to sister and nephews	

Life transition consists in a flow of significant events that precipitate personal mediation, and result in physical transitions and social realignment.

A few additional comments may further enhance understanding of life transitions, specifically the transition to adult life as Tina is experiencing it. First, Tina's growth in independence is linked with the development of old and new relationships. The deterioration of the relation with her brother-in-law certainly affected her relationship with her sister and has led to her living independently in an apartment. However, a relationship of dependency has lingered because her sister retained guardianship. Tina wishes to be independent from her sister. However, she does not think that she can be completely independent without being married, which could be considered as the development of at least some degree of new dependency on a husband. Becoming independent is tightly connected with new forms of dependency.

Looking at the different life periods in Tina's life as they are depicted in Table 3.1, it is difficult to say that they had ended abruptly. Instead, the effect of mediation is that they transform into new life periods. However, older life periods linger on in memory and in occasional encounters. Such is the case for Tina's first life period which took only 11 months but let her think about her "real Mom." It also impinges on more current life periods, for example, her relationship with her adoptive sister. In day-to-day language, she talks about her "sister," but in explaining the situation to strangers, like researchers, she explains that Becky is not her real sister, but her guardian. In addition, occasional encounters may revive these life periods, such as with her father. She says, *"[I'll see my Dad] when I'm down south. He'll speak to me. He'll ask me 'Are you doing fine?' or, 'Are you doing OK?' He'll ask me 'Are you working' and I'll say 'Yeah.' He'll say 'Are you done with school?' and I'll say 'Yeah.' He'll*

ask me all those questions." A ina develops in her current life period, it may well be that her relations with her adoptive sister develop in the same direction as part of a life period that is lingering on.

A researcher of the life course may be fascinated by looking at the extent to which significant incidents have impacted the life course and have determined the success of certain transitions, such as the transition to adult life. However, this research does not attempt to find such a causal relationship; but rather, it advances a hypothesis that stresses the lingering quality of certain incidents. One may consider, for example, the issue of the early child abuse in Tina's life. Certainly, the situation has profoundly influenced her life course and the incidents still have an effect such as the ongoing arthritis in her left shoulder. But to say that the child abuse has made her life miserable goes too far. It goes against the opinions of many people, including her sister, agency personnel, and people at work who have given her much credit.

The Historical Dimension of Life Transitions

Different perspectives on the transition to adult life develop for two reasons. First, because life transitions are intersected with the transitions of other persons, perceptions of change become strongly emotional. Such is the case in both Tina's and Becky's perspectives. Second, Tina's involvement in special education made available institutional resources for her transition which can mediate life transitions. The institutional perspective on transition is grounded in a professional culture and in current legislation. Thus, the transition of an individual with mental retardation like Tina becomes the result of institutional support and the efforts of individuals who are strongly emotionally involved. To place this in a larger

context, both the history of services for persons with mental retardation as it has influenced their transition to adult life and some values that guide American lives need to be considered.

The transition into adult life as it happened for Tina would have been inconceivable without some very important developments in the professional field of mental retardation and in American society. Tina is part of a cohort of individuals born in the 1970's who has not experienced a situation of institutionalization that would have been common practice until the 1960's, when many institutions closed. Instead, by the time Tina was five, important legislation was passed that mandated education for all handicapped children (i.e., P.L. 94-142). Parents who wanted education or professional help were no longer limited to placing their children in an institution. The team became the model for professional help, and the place became the public school. By law, the team became accountable for the development of an individual educational program (IEP) for each child with a disability. Tina's involvement in special education came later, however, probably around the age of eight or nine. Her sister acknowledges the initiative of her mother in this respect.

The continuing development of special demonstration programs is shown by the work program that Tina became involved in during her last year of school. She was given a job in the community as part of this program. Professionals considered whether Tina would benefit from having a job coach who could assist her with her job, but decided that this would not be necessary as she could follow instructions from her supervisor at work. These programs try out employment possibilities for persons with disabilities. Students with disabilities are able to experience real work while they are still in school.

Once Tina's sister Becky contacted the service agency, further arrangements were made for her employment and independent living. A choice of options for employment were

presented, and it was clear from her account that Tina clearly preferred not to try out work at a post office. Similarly, several residential options were explored. The option of living in a group home was rejected because Tina preferred to live in a supervised apartment and had the requisite skills to do so. Evidently, the choices that the agency presented were not unlimited, but the idea that there is a *choice* is a very important idea in the current discussion in special education.

Recently, *choice* has been connected with *empowerment*, the idea that persons with disabilities are in control of their lives and make their own decisions. Over the past few decades, much effort in special education has been spent to train persons with mental retardation in appropriate behavior so that "they could fit in many social situations." Although Tina behaves very naturally, she told me that she applies some of that learned behavior at work. In addition to "managing the behavior of the person," the field has very recently moved toward managing the environment of the individual and planning some of the supports that a person with mental retardation needs in order to be successful. The woman who works with Tina at her job is such a support, and the agency communicates with this woman on a regular basis.

The historical development of the professional culture that assists persons with mental retardation is interesting because it reflects sharp shifts in thinking and policy over time. At least some of these changes reflect a changing American society and life.

Independence and Living the American Life

Americans who are disadvantaged because of socioeconomic status, gender, ethnic criteria, or sexual orientation have been successful in bringing their concerns to the political forefront. Perhaps most widely known, the civil rights movement generated a platform of

ideas from which more recent groups have been able to launch their own rights agendas. The disability movement has certainly benefitted from this visibility. It has directly resulted in persons with many different types of disabilities becoming more visible and finding greater access to the quality of life that others already enjoyed.

It would not be farfetched to speculate that persons with conditions similar to Tina's would have been invisible a few decades ago. Even now, Tina's presence in day-to-day life is limited. She rides a regular bus to and from work, and she visits fast-food restaurants, activities that require only limited contact with other people. At work, it was considered best to arrange a job for Tina in the back of the store rather than on the floor. Bringing "marginalized" people into the mainstream is a recent phenomenon in American society. It is also contested. The economic backlash of the 1980's and the increased visibility of people with cognitive disabilities are interpreted by some people as a deterioration of the quality of American life; for others, their presence brings out the diversity of American society, another highly contested issue.

The transition from school to adult life as Tina experienced it needs to be linked to how that transition is made by young people who do not have a disability. Historical research in this area has established that, over the last century, the events that characterize the transition have become more and more compressed in time and much more demanding on the individual participants (Modell, Furstenburg & Hersberg, 1976). Events such as leaving school, beginning to work, living away from home, and finding and living with a partner happen at much younger ages. It appears that the objective of the legislation that mandates transition services for students with disabilities (P.L. 101-476) had essentially the increase of this effectiveness in mind. After all the children with disabilities had been provided with

education, the next logical step was to create an increased opportunity for employment. In Tina's example, no time was wasted in preparing her for a job and "providing" her with a job at the time of graduation.

The effectiveness of the transition to adult life is highly associated with one of the highest values of American society: independence. It goes back to its democratic principles and is demonstrated in such documents as *The Declaration of Independence* and the *U.S. Constitution*. The independence and identity of American society were until recently confronted in the Cold War. The disappearance of the enemy has led to some lost identity and an increased anxiety that has led to rethinking other fundamentals such as family structure, work ethic, and unity and diversity in American society. The independence of persons with disabilities is of such extreme importance in American culture that it is thought to be part of being human. For those individuals with disabilities who are limited in finding independent lives, commensurate efforts are arranged to make such transitions as work and independent living possible. The amount of assistance, for example, in supported employment initiatives where one individual's job is to assist a person with a disability in work duties, is almost a simulated independence. The *idea* of independence, not necessarily its physical reality, is extremely strong.

Analyzing the Life Course

The conceptual framework for this study relies on what is known as the life course approach (Back, 1980; Hagestad, 1990). A basic idea in this approach is that the transitions an individual makes in the course of a lifetime need to be understood at the intersection of individual, social, and historical time. Related to this research project, *individual time* means one's individual perspective on events in the transition from school to adult life as it relates

to other significant events in one's life. *Social time* means that these significant events can only be understood in the context of the life paths of significant others. *Historical time* in this project reflects the recent shifts of thinking about persons with mental retardation, and how this thinking is reflected in a new definition of mental retardation in terms of support rather than IQ levels (e.g., Turkington, 1992). It also relates to a continuing development of services and legislation that affect the lives of persons with retardation.

Individual Dimension

Time, as we experience it, is continuous; it contains no discrete *events* (Leach, 1990). Events are developed, either by reflection on the past or by anticipation of the future. This is the essence of individual time as psychological process. In a life course approach, *individual time* essentially refers to how people plan and organize their lives and time their transitions (Hareven, 1979). The legislation as we discussed provides a schema for what persons with disabilities could expect from their lives. However, it does not account for the reality of people's lives. In this section, we address the question of how individual lives unfold in the concrete events of everyday life, especially against the premise that lives in American culture are fast and that they can be changed and controlled.

To aid this analysis, the ideas of *life domain*, *script*, and *structure of transition* are employed. As persons with a mental disability leave high school, they are interested in what their futures hold, and so are their parents. Greater independence is the leading expectation of persons in this age range. To meet these expectations, a variety of decisions must be made in different *life domains*, the semantic domains in which events are grouped to form larger entities.

If becoming independent is the standard for measuring success of young adults in American culture, the persons in the study accomplished different degrees of success in different life domains. The definition of transition by Wehman (1992; 1994) identifies five relevant outcome domains of the transition to adult life for students with disabilities: employment, independent living, self/sexuality, peer relations, and independent mobility. This definition follows the current trend toward planning interventions according to domains and identifying outcomes in these domains rather than in terms of a medical syndrome. The legislation that defines transition as an outcome-oriented process (IDEA, 1990) has, at least in part, stimulated such idea.

While figuring out a future, a mental image in which events from several different semantic domains is developed into a coherent *script*. Such a script is the result of the negotiation inherent in an event and how events are reflected upon in time, that is, before and after they happen. The term *script* is useful in developing a hypothesis about the process of a series of events and developing insight into the nature of individual lives (Buchmann, 1989). Here, the term indicates the sense of how different stakeholders in the transition process negotiate events and carve out a niche in adult life. In this sense, the script is an outcome. Perhaps more accurately, the script reflects how stakeholders write a text that will separate the person from childhood and launch him/her into adult life. Although scripts are outcomes, they also become the basis of guiding images that need to be further pursued, modified, or abandoned.

The questions then become: How are adult lives written? What are the dynamics of this process, especially as it relates to the life course of non-disabled young adults? Further, to come back to an essential theme: How does the construction of the life course demonstrate

essential premises of society? A greater number of potentially available roles than ever before characterizes the life course of young non-disabled youth, but the institutional structures within which the persons must fit constrain the choices (Clausen, 1991). Education is one institutional structure that provides a substantial degree of structure and scheduling for the individual life course. Adult agencies are another. The historical context of the lives of the persons in this lies in the premise that an equal education would lead to a more satisfactory adult life.

The third important concept here is *cultural schedule*. Contemporary American society provides a cultural schedule that suggests that individual lives are highly changeable in the sense that they are very movable and that several sections of the life course can be repeated. But how does this experience compare to that of people with mental disabilities? Clausen (1993) is correct in his assertion that society provides rough scripts for the life course of its people. However, how a particular script is written is mediated at different levels. For persons with mental retardation, the writing of their particular script is the outcome of a specific set of values in a particular historical time that directs the expectation and actions taken by other people. Unlike the culture of people with disabilities such as deafness, blindness, or physical disabilities, the culture of retardation can be conceptualized by an enormous web of people and institutions that guide and direct people with mental retardation. Becoming part of this culture means submitting oneself to the power structures that go along with this culture. Only very recently have initiatives by people with mental disabilities themselves been forthcoming. Script-writing has mostly been directed by changing professional priorities. The legislation has been a major tool in assisting the writing of a script because it determines the eligibility for resources. Legislation that makes education

available to all children with disabilities is in this sense supportive of writing a script. It is in turn based on larger movements in society, like the civil rights movement, and based on the assumption that providing education to all people is a ticket to success. These ideas eventually become cultural schedules which in turn direct action. While the right to education became available to most of the individuals in the group, it did not automatically provide them with a ticket to success. Following the reaction to the failure of a cultural schedule, both at the cultural and the individual level, is instructive for the interactions between cultural schedules and individual action.

Essential in a life course framework is to look beyond the individual dimension of lives and to appreciate how lives are shaped within their social, historical and cultural contexts. This applies also to topical sections of the life course, such as the transition to adult life. To make such an approach operational, one may start in one of these dimensions and explore it until reaching its limits. At this point, connections must be made between other dimensions. The next three sections take the individual, social, and cultural dimensions of the life course, respectively, as starting points for analysis and broaden into other dimensions.

Individual Life Domains. At the individual dimension, the events that take place or not at the time of transitioning into adult life are the primary units of analysis. Such events may eventually be used to evaluate a general quality of the lives of persons with disabilities. In life histories, the persons with mental disabilities, their parents, and service providers give accounts of the events that happened. While concrete events and the general quality of life could both be used to compare several individuals, *life domain*, as an intermediary concept, is more useful for comparison and analysis. An evaluation of different life domains amounts to an overall picture of the quality of the transition to adult life. It also serves to evaluate

concrete events. Looking at different life domains will be the first step in the analysis of the individual dimension.

"The life course is essentially a sequence of events" (Harris, 1987). Out of this proposition, two questions evolve: what happened in this person's life? and, how did it happen? By describing and comparing life domains, an evaluation can be made of how all individuals are faring in their early adult lives. The next step then is an attempt to provide a rationale for why they are doing as they are. Whereas individual life domains portray a static picture of the adult lives, the development of life scripts attempts to describe the process of how these outcomes developed.

Based on the life history material, and in concert with others who happen to know the persons in the study, mostly because of their involvement with the study, an informed decision was made about the deficit areas in independent functioning of all individuals in the study. Table 3.2 reviews these deficit areas. A horizontal reading of the table shows how each person is doing in various life domains. This may function as an informed judgment of the success in independent living for each person. A vertical reading shows areas that are more or less problematic compared to others.

Following a vertical reading, several life domains may be compared. The domain of peer relations proves to be most problematic for most persons in the study because they involve relations at work and in living situations and involve jealousy toward peers, domination of one another, and arguments that sometimes evolve into violence. There are also problems that relate to hiding incompetence, not fitting into a group, and being ignored. Those who are doing well in this area have developed different strategies. For example, Tina manages her friends by communicating with them on a regular basis and participating in

Table 3.2

Incomplete Outcomes in Selected Life Domains

	Work	Independent Living	Self/ Sexuality	Peer	Independent Mobility
Steve			√	√	√
Peter				√	
Lori	√	√	√		
Sharon		√	√	√	√
Brian	√	√			√
Timothy				√	
Tina					
Mike				√	
Joyce			√	√	
Dennis			√	√	
Diane				√	
Justin	√	√	√		

mutually arranged activities. Lori has learned to keep conversations going with phrases and small talk, without getting very involved in relationships. Justin is task oriented and avoids most people within his service agency, especially those who are known to be violent; he maintains many of his friends from high school, from his neighborhood, and from his church. The domain of self/sexuality is the second most problematic domain, with half of the individuals experiencing problems, such as a damaged self-concept which is sometimes connected with undeveloped relations with other people and a lack of sexual integration. The two domains of peer relations and self/sexuality may be problematic because they are in the sphere of privacy. These are, for the most part, not the primary areas that service agencies target.

Work, independent living, and independent mobility are interconnected areas for an individual to become eligible for services. In other words, when a person expresses an interest in working, then living near the workplace and independent transportation to it become necessities. The relative success in these areas is frequently the result of services provided to the persons with mental disabilities. All the persons who were identified as having a problem in the domain of independent living were living with parents. Lori, Sharon, and Brian all live in rural areas. Their parents did not push them to seek independent living because they do not see living in a larger city as practical or desirable. Lori lives as a nearly invisible person in her parents' home. She disappears into her room as soon as she gets a chance and comes out only when her mother calls her. Her volunteer, unpaid job does not induce anyone to help her to make changes in her living situation. Some, like Sharon's parents, have seen a group home in their town but did not find it a suitable solution because they did not want to see their daughter live with people who are more severely disabled than

she is. Living in a community apartment, on the other hand, is an alternative that is also not unfeasible because they do not believe Sharon could manage on her own, and consequently, they would have to assume most of the responsibilities. Although Brian's biggest dream is to move out of his parents' home, the absence of a job and the comfort of his parents' home are not stimulating him to take the initiative.

People who are not independently mobile must rely on their service agencies and parents for transportation; they have no transportation alternatives for going to work or any other place. Although Steve could ride a bicycle and decide upon certain places he would like to visit, he prefers to rely on others for transportation. Because of the lack of public transportation in rural areas, Sharon and Brian became totally dependent upon their agencies, in which they are bussed to work or to the mental health center. Most of the persons in this study used public transportation effectively. For Timothy, who uses an electric wheelchair, using the bus has been a source of intense frustration. The local bus company has experimented with different types of lifts but not all of them have proven to be mechanically sound. It took a huge effort from his parents to convince the bus company to construct a concrete platform at the bus stop Timothy uses. Although Timothy takes the bus every day, the bus company has not found it necessary to send one of the newer buses on his route. Timothy also needs to deal with the insensitivity of some of the bus drivers. In addition to public transportation, many persons just walk. Some persons, who have to take more than two buses to get to work, prefer to walk than to wait for the bus. Peter is perhaps unique in his use of the bicycle. He travels all over town and has no limitations on places he can go.

Transition Scripts. Although an overview of life domains may be indicative of the independence that the persons enjoyed, this evaluation needs to be supplemented with how

these outcomes were achieved. Table 3.3 the summarizes the important characteristics that determine the development of young adult life scripts and current life domain outcomes. For clarity, the scripts were labeled using descriptive terms that best represent the quality of the script.

Tina: "liberated" script. Tina's transition to adult life reflects the impact of both liberation and dependency and the strong ties between both. The mediation of her adoptive sister opened the way to independent living in an apartment and being relieved of an emotionally uncomfortable family situation. Becoming independent opened the way in turn increased the gap between her and her family, with the legal arrangement of guardianship between her and her adoptive sister as the last stronghold. The disjunction between her former social group is almost complete as even Christmas was not spent with her family. She is sad because she misses her nephews but sees the break as complete and as a loss. New social alignments with her friends and especially her boyfriend, and the occasional support from her apartment supervisor, have become her model for building a script of adult life. Interestingly, the release of dependency from her adoptive sister seems to be impossible without the forging of new dependence on her boyfriend, which will only be complete at the time of her marriage. Her entry into employment was negotiated by her service agency and had a strong input from Tina in refusing initial job proposals.

Tina's outcomes are situated at the high status end of the service agency's programs. At entry, and as a result of the mediation of her adoptive sister, Tina waited until a supervised apartment became available, thus avoiding any involvement with a for Tina to be happy and meet a large number of people who could be her friends, which group home. Tina's living situation will likely result in her living in the community depending on how her relationship

Table 3.3

Adult Scripts

	Script	Transition Markers	
		Physical Markers	Social Markers
Steve	**"AGENCY" SCRIPT** 1. Strong socialization in the service agency; 2. Social and physical disjunction with the past; 3. Complete release of parent responsibility; 4. Negotiation limited to daily activities.	Group home	Agency friends: group home, sheltered work, imagined girlfriend
Lon	**"PROTECTION" SCRIPT** 1. Stringent socialization in the service agency; 2. Continuity/strengthening the past; 3. Inability of release of parent responsibility; 4. Negotiation within a protected relationship	None	None
Timothy	**"FAMILY" SCRIPT** 1. Reluctant socialization in the service agency; 2. Physical disjunction with the past; 3. No release of parent responsibility; 4. Negotiation of life domains	Supervised apartment	None
Dennis	**"FRIEND-EMPLOYER" SCRIPT** 1. No agency connection; 2. Continuity of the past; 3. Complete release of parent responsibility; 4. Individual negotiation of life domain	House	Girlfriend - employer
Tina	**"LIBERATED" SCRIPT** 1. Liberating effects of service agency; 2. Growing in complete disjunction with the past; 3. Release of family responsibility, except legal; 4. Partial negotiation, e.g. employment	Supervised apartment	Boyfriend - friends
Brian	**"PLACE-TO-GO" SCRIPT** 1. Agency provides a place to go; 2. Continuation of the past; 3. Supervision release of family; 4. No negotiation.	None	Imagined girlfriend
Sharon	**"RELATIONSHIP" SCRIPT** 1. Incompetence assumption; 2. Continuation of the past; 3. Responsibility in all domains except employment; 4. No negotiation: family script imposed.	None	None

with her boyfriend evolves. Tina also bypassed any involvement in a sheltered workshop environment and successfully negotiated a community job. In many ways, Tina's sister played an important role as a life transition mediator. However, as any other mediator, Tina's sister experiences the paradoxes that accompany that role: by definition, mediators become unnecessary once they have played their role. If they insist on continuing to play a role in the life of a person, they may be experienced as a burden.

Steve: "agency" script. Unlike Tina, Steve's script comes very close to full control of the agency over Steve's life. When Steve's school facilitated the contact between the family and the service agency, it was quickly understood and negotiated that, in order for Steve to be employed, he would also have to come and live in the nearby city where the agency was located. If he did not move, daily transportation from home to work would be impractical. For Steve, this meant a complete change in his life and a strong disjunction with his past. The parents were both overwhelmed and impressed with a tour of the agency services. This resulted in a complete release of parental responsibility and their loss of control over daily decisions. The telephone calls, weekend visits, and seasonal holidays were insufficient compensation their for sudden loss, emptiness, or for Steve's loneliness and loss of control. Once this control was released, Steve never managed to regain much control. Instead, his problems at the group home make his frustration and loneliness even greater. Steve likes to exchange clothes with other clients, a behavior the agency does not accept, and, in the agency bus and at work, he occasionally has conflicts with other clients. Based on this evidence, the agency staff concludes that Steve is "not ready" for more independent living or working arrangements. The agency's interventions are geared toward modifying his deviant behavior with specifically designed behavior modification programs. Steve is very encapsulated by the

agency. His scripting of the future is no longer derived from the outside world, but from what the agency has to offer. Some of the outside world norms take on a symbolic form. For example, having a girlfriend and having a car are both important markers of adult life for Steve. Steve's "having a girlfriend," however, is limited to a daily goodbye kiss with a girl at the sheltered workshop. At least on occasion, his group home roommate was also permitted to do the same. Similarly, Steve dreams of cars; he has a large collection of model cars and Matchbox toy cars that he likes to bring to outings for the purpose of displaying them and occasionally exchanging them. However, the idea of really obtaining a car has taken on unrealistic proportions, both in choice and strategy. Steve dreams of owning a sports car but has little idea of the skills that are necessary to pass a driving test. He also has unrealistic ideas about the financial implications of owning a car, except for the knowledge that it will be difficult and that he needs to keep on working hard at his job. Steve has limited control over daily transitions. Even this control is explained in terms of limited choices that go along with the planning of the agency. For example, he may have some control in deciding on which day of the week he will be responsible for cooking, but he may not decide that he will not participate in the cooking. The planning process in itself is also controlled by the agency group home in a weekly meeting.

Steve's life domains are very much determined by the agency, and this probably will endure in view of Steve's limited control and insight. He will grow into services which are of higher status in the organizational structure of the agency. From a sheltered employment job which is minimally paid he will most likely move on to a higher paid contract job and ultimately into a community job. His living situation will change from a group home living situation to a supervised apartment and maybe to a community apartment in the distant

future. Steve compares his current situation to that of other persons who also receive services from the same agency. The constant stream of people in and out of the group home and the working situation gives him clues about what his situation may become. Without effective initiative from him or his parents, the question becomes: "Who needs to be ready in order for these changes to occur: Steve or the agency?" The answer, of course, is, both.

Brian: "place-to-go" script & Sharon: "relationship" script. From the life histories of Brian and Sharon, one is able to learn other aspects of the individual dimensions of life as they become reflected in scripts and outcomes. While Steve and Tina may somehow be characterized as successful in finding niches and in increasing independence, such can hardly be said for the lives of Brian and Sharon. Both live in rural towns and both have not found moving into more urbanized areas beneficial. Instead, both see the advantages of staying in the more rural setting. The situation of both persons may be described as being stuck, although it takes on different qualities for both persons. For Brian, space has been the dominant issue. Sharon, on the other hand, seems to be stuck in relationships.

Brian's life history demonstrates the impact of multiple disabilities, both mental and physical. Overcoming these disabilities is an enormous challenge. Brian's mother is very much alone in her endeavors to make things happen for Brian. Her moving back to her own hometown and providing the closeness of family members and the intimacy of a small town is her contribution to Brian's life. Although she does not see any alternatives to relying on service agencies for Brian, she is painfully aware of their limitations too. Because Brian's communication is severely limited as a result of cerebral palsy, his mother has taken over Brian's voice. The agency providers become for her an alternative to a life that is rather empty and to provide her son with a place to go, a break in the deadly routine of being trapped in the

house. Brian's involvement with the agency, however, has opened avenues to explore. It is here that Brian has learned that his goal should be to move out of his parents' house and live independently. However, his goal cannot easily be achieved as long as a job can not be secured, which is hard enough in view of his disability, let alone the lack of opportunity in a rural environment. The form in which independent living should take place is another issue. Both his service agency person and his mother see living independently in an apartment with a roommate as ideal. Brian's involvement with the agency also created the opportunity for social activities, something both his mother and vocational coordinator applaud but which seem to be rather unimportant to Brian. Instead, Brian finds the acquaintance of a woman at the agency of far greater importance, even though both his mother and his coordinator do not see the relationship as amounting to anything meaningful. In many ways the agency serves the role of a sheltering environment for Brian and for his mother. The expectations of any change in the situation are low. Brian's vocational coordinator has the responsibility of securing a job for Brian. It is assumed that training, and lately, the input of computer technology will lead to this job. It is also believed that a job will be the key to Brian's transition into adult life. With the lack of skills and opportunity, Brian and his mother have low expectations and are satisfied that, at least for now, Brian has somewhere to go.

From Sharon's life history, the importance of relationships in working out a plan for the future is clear. Her script of a future adult life is essentially one of socialized incompetence, meaning that she has learned to think of herself as incompetent. Socialized incompetence has been described by Langness and Levine (1986) as the condition in which many persons with mental retardation perceive themselves incompetent as a result of their interaction with society. In Sharon's experience, people are extremely destructive of any

competence she intends to portray. Sharon has been instructed to cover her disability through neat grooming and small talk. However, in enduring relations this coverup is easily seen through, leading to intense frustration. Sharon's mother is instrumental in breaking the cover with other people. Edgerton (1993) has described this coverup as "the cloak of competence" and generalized for the experience of many of the people with retardation who were exiting the institutions in the 1960's. The concept seems to explain the experience of Sharon well, but is less accurate for the experience of other persons in the cohort. Relationships with other people are destructive for Sharon and this transpired also in the research relationship, which became uncomfortable on both sides as it progressed. Sharon is enormously attached to her dog; understandably, he will never unveil her incompetence.

Sharon's perspective of incompetence permeates many of the adult life domains. She is adamant in her conviction that she will never drive a car and never leave her home to live independently. The domain of self/sexuality is systematically outruled in her mind as a result of negative, destructive experiences. The only domain in which Sharon experiences some success is work, partly due to a relationship with her supervisor at the nursing home where she works. Sharon's mother is grateful that "they are going out of their way in putting up with her." A breakdown in this domain would only confirm for Sharon and her mother her persisting incompetence.

The Structure of Transition. If the life course is essentially a sequence of events, as Harris (1987) claims, taking control over these events and giving meaning to them in a coherent whole, as in a script, is a human characteristic. Harris's view of the life course is useful in analyzing the individual dimension of the life course, but the definition is limited, as it ignores other vital dimensions. Taking control over these events is a developmental process

that starts early in life and gradually progresses as cultural schedules and personal experience sort out life courses which, influenced by historical time, are the outcome of social interaction and individual characteristics. Children in all cultures take great interest in what they will become and early on copy models and develop individual scripts of their future. In the lives of people with mental disabilities, the structure of scripts takes a particular form, which results from personal experience, socialization, and the expectations that are in the context of a particular historical time.

In discussing the transition to adult life, Tina's life history was used to show her transition as a life transition and to show the process of this transition. However, this transition is important in the context of a whole life; for all the persons in this study the daily life of persons with mental disabilities can hardly be understood by focusing on the life dimensions only. In order to provide a complete insight that also takes into account the daily preoccupations of persons with mental disabilities, transitions at two other levels are considered: *daily transitions* and *seasonal transitions*. Table 3.4 outlines the markers of these transitions at different levels.

The structure of transition scripts needs to be evaluated by looking at three levels. Taking the three levels into account, the development of these scripts for four individuals is described. In their development, the impact of the different players or stakeholders in transition is clear. The following sections describe the development of young adult scripts of Steve, Peter, Timothy, and Mike. All these persons were in contact with the same agency. However, the outcomes in their situations were quite different and largely the result of negotiations among parents, agency personnel, and the person with the disability. These negotiations lead to scripts that are consequently written more in terms of the agency or more

Table 3.4

Levels of Transition

Level	Transition	Events	Markers
One	Life	Life period characterized by events, social voids, and intersection	Social realignment and physical changes
Two	Seasonal/ Year	Christmas, Memorial Day, Labor Day, Thanksgiving; Birthday	Public and/or private expressions
Three	Daily/ Weekly	Activities of daily living; Planning and "getting ready for the next thing"	Living, work, and recreation

in terms of the parent or individual with a disability. This negotiation has a important impact on the status of the individual in the agency.

Negotiating Peter's transition script. Level 1: life transition. During high school, Peter lived with his adoptive parents and brother on a farm. Because of Peter's disability, Peter's mother adjusted her career to special education and became a vocational coordinator. Peter's mother and father wanted their son to be independent. Peter's mother talks about Peter's problems of becoming independent and the need for her involvement:

> *Even though Peter has been introduced to career awareness, his maturity level was that he didn't know the value of work or why you work. Even though you have to make money, he didn't want to make the decision of having to go to work. At times, he much would have rather sat on a farm and work for Dad. We didn't want that. We wanted him to get out and get more experience from other people and go out into the world. He went with me and I had him put down for an appointment in a summer youth employment program. With that he did really good. He worked with two older gentlemen aged 60. He did a beautiful job. He was out being hyper-active, he was out working outside, doing things, physical labor.*

Peter's mother took the initiative in exploring services after high school and found that only one agency was available that could help in arranging a living situation and work for Peter. Independence was the most important motive. She stated, *"What we are trying with [the agency] is get him off."* Through her professional network, the mother contacted a state vocational agency and also arranged for Supplemental Security Income (SSI). The vocational agency carried out vocational assessment and used the information in discussion with the agency. The outcome of further assessment by the agency was that Peter would be provided with an apartment and be placed on supported employment. The mother accepted this

situation as a starting point. However, she did not agree with some of the arrangements and found in the process that her input did not count much. She said, "He's got an IQ of 95. He should not be on supported employment. He should be going on work experience at a community job." She also found that the agency took too much control over Peter especially as far as his checking account was concerned. Apparently, Peter has had a checking account throughout his high school. He deposited money he earned from work on the farm, and mowing the lawn, and an allowance, and he was required to buy certain things with this money to teach him how to handle money. While he is at the agency, he writes checks from his account, but his apartment trainer keeps track of how much money he has and logs it for him. The mother concludes, "He never knows how much money he has in his checking account. He thinks there will always be money there. And therefore the ownership of that checking account does not belong to him."

What the mother perhaps has not realized is that her son's entry in the agency was perhaps much better than it would have been if she had not actively negotiated. This became clear from listening to Sarah, a group home worker who placed clients within the culture of the agency. According to her, this culture is created by the array of services that are being provided, the status that is assigned to the service, and the barriers that one must overcome to move from one service to another. In terms of employment, Peter had skipped the lower paid employment, which is available in the sheltered workshops, and was offered a community job instead. Through much of his own negotiation and the problems he created at work, Peter obtained an even better job in the kitchen of an Italian restaurant. In terms of living arrangements, Peter skipped the lower-status living in a group home and was accepted to

lhive in a supervised apartment. Because of the problems he created there, the agency was quick in arranging a community apartment.

In terms of his recreation, Peter again took the initiative himself. His parents had observed the Friday evening recreation that was organized by the agency and decided that this would not fit their son's needs. Instead, they had wanted him to become involved in recreation and leisure in a non-disabled population, so that he could learn good social skills. However, Peter became strongly involved with a girlfriend, a situation that came to an end after the two got into the fight, a window was broken, and the police had to intervene. The incident was sufficient to persuade the agency that Peter needed to move away from his supervised apartment and to organize a community apartment, and break up with his girlfriend, ensuring that she would not know his new phone number, and at the same time maintain his employment in the Italian restaurant.

Much in tune with the speed of life in American society, Peter and his family managed to change his life at a very fast pace. Negotiation, making events occur, and building new plans made Peter move extremely fast. Peter's explosive energy also contributed to making the agency move faster on his requests than they would have moved with other persons. Peter's parents intervened in the sequence of events and they advised him on putting his priorities straight. However, it was not until the incident that lead to the break up with his girlfriend that the agency helped him in moving into a community apartment, and that his parents helped him to break with his old friends--his new telephone number was not listed in the phone book and Peter was advised not to give it to anyone--and to concentrate on work and earning money.

Level 2: daily living. Peter's daily living transitions are structured by his employment, his living situation, and his free time. Peter has a long history of behavior modification programs for his hyperactivity. According to Peter's mother, "These programs have been good to achieve what he needed to achieve at the time, but it's been bad because he never internalized for himself that he achieved something." Peter also received a lot of medical counseling and was put on many different kinds of medication, none of which, according to his mother, really lessened the hyperactivity to any degree. In his file, the complexity of his medical situation was stated by one doctor as follows: "Mr. Woods has a variety of difficulties. Many of the diagnostic statements which can be made represent more a statement of our ignorance in understanding his fundamental problems than any positive summarization of his situation." Despite this statement, Peter continues to take different kinds of medication. He finds his medication to be the primary reason for not being able to drive a car, as it slows down his reaction time. Peter takes the bus to work, and occasionally his bike. During his free time, he rides his bike all over town.

Behavior modification programs continue to be part of Peter's daily life experience. As he started to get into problems with his peers at his supported employment place or in his apartment, the agency initiated a program which included that he was sent home and not allowed to work on the following day. Peter's parents became upset with this arrangement, as they found it an infraction on their rights.

Level 3: linear time structures. While time is well defined in the United States, breaking up the week into a work part and the weekend, and breaking up the year into clear markers, Peter's work blurred these structures. He works from 9am to 3pm from Friday through Tuesday and has Wednesday and Thursdays off. He also works on certain holidays.

These arrangements make him concentrate more on work and less on his family. He spends his free time with his girlfriend and with his pets.

Negotiating Steve's script. Whereas Peter has moved relatively quickly into higher status positions in his service agency, Steve's situation has been somewhat static. The school coordinator had made the contact with the service agency. In the initial negotiation with the service agency, Steve's parents had to accept that the agency could not arrange employment for Steve without Steve also living in the area. Likewise, according to federal legislation, no living arrangement in a group home would be possible unless the person was actively involved in a day activity. Steve's parents were given an introductory tour to acquaint them with the various services that are provided. Steve's mother was impressed with the variety and quality of the programs. On the basis of vocational assessment and psychological testing, it was decided that Steve would live in a group home and work in the sheltered workshop. He was subsequently introduced to living in a group home by staying overnight a few times until he moved in to his first group home. The agency worked with him, teaching him to do his job at the sheltered workshop and teaching him to ride the bus to and from work. Steve had to become acquainted with the culture of mental retardation, learning about all the rules at work and at the group home, and learning the consequences of breaking these rules.

As his parents did not take much initiative in negotiating Steve's situation but merely accepted it, Steve himself also did not exert much influence on his own life. His impact on his life became very limited, and much of his concentration concerned following the rules. He became caught up in his conception that it was fun to exchange clothes with other group home members, and he was put on a behavior modification program to change his behavior. He also did not develop a script of adult life in a non-disabled world, but one within the

confines of the service agency. As he became friends with Peter and some other people at the group home and at work, his outline of his future came through comparison with these people's lives. Steve found out that, although he is a few years older than Peter, his situation is in no way comparable to Peter's. Peter had a steady relationship with a girlfriend, where as Steve's relationship was much less determined; Peter was working at a supported employment job which paid more than Steve's sheltered work job; Peter lived in a supervised apartment whereas Steve lived in a group home. From these comparisons, Steve developed an intense jealousy of Peter and teased him and his girlfriend on many occasions. While he created problems during the day, he would call up other friends and rally them, and seek their support. His relationship with Peter deteriorated from these incidents and led to a point where the agency intervened and banned him from visiting Peter or calling him on the phone. At the same time, the agency became convinced that Peter was too immature to be moved to a more responsible position. Steve's remaining wish is to live in a supervised apartment like some of his group home friends.

While Steve developed his script more and more in terms of the agency, any reference to an adult script outside the agency became somewhat blurred. His friends from high school functioned somewhat as an anti-model, especially as he heard from some of them who had been involved car accidents. Steve has a strong interest in cars, but this interest is devoted to his toy cars which he likes to buy and trade. The idea of really driving seems far off, especially in view of his economic situation and the cost involved in owing and maintaining a car, and his ability to pass a driving test.

It is fair to conclude that Steve's script of adult life has been pretty much dominated by the agency. Steve's parents did not exert any influence over his situation but merely gave

the agency *carte blanche* in taking care of Steve. Steve's parents find themselves limited to taking responsibility for what they conceptualize as outside the sphere of the agency. They occasionally call Steve and visit him at his group home during the weekend, and take him home for some weekends and for holidays. Perhaps the difference in professional background may account for much of the different styles between Peter's and Steve's parents. While Peter's mother has moved her career in the direction of special education and became well versed with available options and the state of the art, Steve's parents relied solely on professional input for decisions regarding Steve. They agreed with the agency's interpretation that Steve is immature and needs to grow in different areas before decisions could be made.

Negotiating Timothy's and Dennis's scripts. To elaborate further on the development of young adult scripts, the scripts of other individuals and their parents who have been fairly successful in shaping their individual life course are discussed. From Timothy's life history, one can learn how important negotiations with the agency can be in determining the outcomes of the transition process and how such negotiation can downplay the potential negative consequences that can be attributed to disability. At Timothy's graduation, Timothy's mother was referred to an adult agency to work with them in planning Timothy's future. The outcome of the encounter was not very positive. Timothy's mother entered into the negotiation with a preconceived idea that she would not allow her son to work in a sheltered workshop, following the advice of a friend who had told her, "Once Timothy enters into a sheltered workshop, he will never get out." The agency was disappointed to inform Timothy's mother that no community employment was available and that sheltered employment would be the best solution in view of Timothy's skills and capabilities. The agency indicated that while Timothy worked at the sheltered workshop, they would search for alternative

employment for Timothy. When Timothy's mother maintained her position, she was told that the adult agency would not be able to help her at that time. Timothy's mother reflects on this, saying that the agency was ready to take all control over her son out of her hands or do nothing at all. There was no room for negotiation: it was their way or my way. The immediate result for Timothy was pretty bleak. He spent the year after high school graduation at home in a rural area. Timothy's mother understood that her son was going to have to move out of her house if he was to have any future at all. She kept on looking for alternatives and eventually came into contact with a federally funded project. As she worked with them, they secured a summer job for Timothy. This job required that Timothy also move out of his house and learn to use public transportation. As this initial move was being worked out in that summer, the prospects looked bright. The summer job was turned into a regular job. Timothy also enjoyed living in a community apartment. However, the cost of the rent was too high in relation to Timothy's earnings. This stimulated Timothy's mother to return to the same adult agency and request a living arrangement for her son. She was motivated because the living facilities were subsidized and more affordable. Because Timothy now had a history of living in an apartment, he was offered an apartment in a building that is supervised by the agency.

Timothy's mother has continued to negotiate for her son. She has also continued to function as a satellite for her son, going back and forth in providing daily service and negotiating the world for him. A registered nurse, she became Timothy's personal care attendant. As a person in a wheelchair with limited mobility and in need of daily care, he is eligible for daily services that help him to sustain an independent life. Timothy's mother works nights and at the end of her daily work, before going home, she assists Timothy with personal care, such as dressing and showering. In addition, she also takes care of his laundry.

She states that Timothy would be able to do his own laundry but that it is just much more convenient if she takes care of it.

Timothy's transition to adult life is generally interpreted as successful. He lives independently in his apartment and is a state employee. However, Timothy's social life has changed little. His most important social group continues to be his family. He sees his mother every morning and makes it part of his routine to call home as soon as he enters his apartment after work. Being safe is a great concern in Timothy's life. As Timothy's mother lives about 30 miles away and works at night, she cannot be available all the time. Out of this concern, and with the help of both his family and agency, a plan was made to create a network of persons on whom Timothy can call in the event he needs someone. In Timothy's apartment, a board is centrally placed with the names and phone numbers of different people. For his convenience, Timothy only has to punch in a number on his phone set to call the person. One person, a friend of his mother at work, has agreed to be a back-up in case Timothy needs personal care and his mother is not available. In such an event, the friend is paid for his services.

The independence that Timothy enjoys is due to the vigorous negotiation and mediation which his mother constantly offers. Timothy is much more limited than Steve in many ways. Timothy's cerebral palsy and his speech disfluency make him a much slower person than Steve. Despite these limitations, Timothy managed to lead a much more independent life.

Life Course, Agency Scripts, and Cultural Schedules. To understand more fully how adult scripts of young people with mental retardation unfold, developments in the life course, the historical background of agencies, and the way American culture transforms itself

must be examined. The people in this study were mostly born in the beginning of the 1970's with a few born closer to the mid 1960's and the mid 1970's. The one important historical experience of this cohort is the absence of institutionalization and their overall experience of integration, albeit emotionally painful for some, partly because of schools were inexperienced in working with persons with disabilities. It turned out that many persons in the study referred to school as a negative experience, especially in terms of its social conditions. They spoke positively, however, of special education as a relief from the harder work that was expected of non-disabled students. In the development of adult scripts, it is obvious that for all of the persons, with the exception of Joyce, who continued school, further education was too heavy a burden. Such a choice places the persons in the 50 percent of American youth who do not continue education beyond high school (Glover & Marshall, 1993).

Two somewhat contradictory historical developments in the life course are important: increased institutionalization and an increased idiosyncrasy. Kohli and Mayer (1986) have argued that the institutionalization of the life course, as the regulation of the sequential course of life and the structuring of the life-world perspectives, is the result of the transition to modernity and can be understood as a process of individualization. Recent historical developments in the services for persons with mental retardation reflect the transition to modernity and the process of individualization, but rather than increased institutionalization, however, it can be argued that the institutionalization of the life course of these has been dramatically transformed in recent years.

Another characteristic of the life course relates to the chronology and presence of events that mark the transition to adult life. In this connection, the distinction has been made between event transitions, where change starts with some non-age-graded event, and

age-graded transitions, which are complexes of event transitions in which the chronological times of onset are normative in the population (Featherman, 1986). Over the last century, the events that mark the transition from school to adult life for non-disabled Americans, such as work, leaving home, and marriage, have been characterized by "compression" (Modell et al., 1976). These events are not spaced out in an orderly sequence but take on idiosyncratic forms, leaving much of the decision-making to the individual. The adult scripts of the persons in this study differ considerably, but there is not the same amount of compression in their life courses for several reasons. First, their options are more limited. For example, for most of the individuals in the study, further education is not an option. In addition, some life domains, especially in the area of sexuality and marriage, are not considered realistic, and the person is discouraged from developing in these areas. Second, persons who have contacts with adult agencies are strongly socialized within the culture of the agency.

Influenced by federal law and other discourses on mental retardation, the recent history of adult agencies may also shed a light on the nature of the unfolding of adult scripts. There are two metaphors that guide the activities of the Illinois agencies with whom the persons in this study worked. First, these agencies have a history of changing from a medical model to a services model. Several parents indicated that agencies like to obtain a great amount of control over the person with mental retardation. Such control is still derived from the medical model, in which a person with mental retardation is considered to be sick and his rehabilitation becomes the responsibility of the agency. The change to a services model has gone hand in hand with the infusion of a business model (see Albrecht, 1992). Professionals who work within the parameters of a services-business model think in terms of "allocative contexts" (Stone, 1991), that is, they think in terms of open slots in the full array of services.

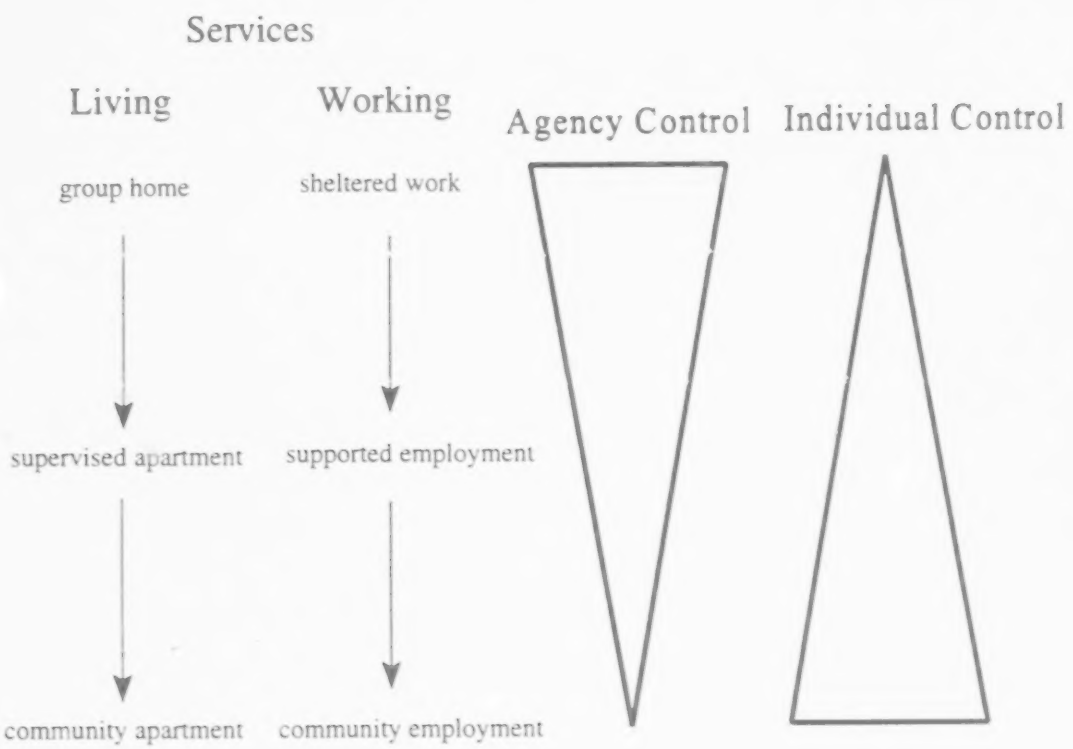
Second, they think in terms of favoring the business component of the agency. It is in their interest that the agency and their own positions be safeguarded. The safeguarding of the professional entourage of persons with disabilities has been examined in a historical context (Trent, 1994). The business model has a conservative impact on the independence of the person, because as a business, the adult agency's objective is to stay in business.

The adult agency develops a script of services for its clients, depending on its array of services. Figure 3.1 lists the array of adult services provided by one agency. These services represent different ranges of control and independence. The scenario that the agency envisions for most of its clients is increasing growth in independence and responsibility. An entry-level situation would be to live in a group home and be employed in a sheltered workshop. This situation represents services in which the agency exerts maximum control over the individual, and in terms of a business model, the agency benefits most from the presence of the person.

Ideally, the person moves on in the organization and gains in control and independence. Such a representation of services is a replication of cultural values that favor hierarchy and moving on in an organization. The agency representation of services goes along with the allocation of prestige. For persons with mental retardation, it becomes a powerful measure for orienting their own lives and judging their relative positions. The continuing jealousy between Steve and Peter can be understood in those terms. Peter is in each of the services positioned on a higher rung, although he is younger and came later to the agency than Steve. While individuals learn about the hierarchy of services in the agency and model their personal scripts after the agency scripts, outside normative scripts lose much of their meaning. This is apparent with persons who are strongly involved with the agency. Steve's

Figure 3.1

Adult Agency Strategies in the Design of Adult Scripts



script is to be able to live independently in a supervised apartment. His models are his friends, such as Peter whom he regularly visited there, and one of his former roommates, who moved into such an apartment. While this is a clear objective, most other domains are rather vague. Steve was told that he needed to leave home to make money, but the amount he earns in the sheltered workshop is insignificant and loses its meaning in terms of food and living. Many of the activities of earning money become symbolic, as they do not have serious implications. As part of the agency, Steve's world becomes a world in its own right, a culture with shared beliefs and rules. This is not the case for many other people in the study who have not accepted some of the terms set forth by the agency or who live completely without agency assistance. These individuals retain part or all of the normative rules and scripts in American culture.

In defining the socialization of persons with mental retardation, Levine and Langness (1986) argued that it appears almost as a cultural conspiracy which produces an effect quite the opposite of that intended. This statement is appropriate in its institutional intent, but must be modified for its outcomes. While parents and persons with retardation are confronted with a cultural tradition that denies that persons with mental retardation learn or understand many of the ordinary facts of everyday life, some parents understand that this structure is not totally closed. They explore the space of negotiation and work out some of the dimensions of their son's or daughter's lives. It is these parents who say of the agency: "*By now, I must be a thorn in their side.*" These parents do not choose the easy way, and many are in a continuous struggle to safeguard some of their own orientations. However, in many cases their mediation is rewarded in the long run with greater independence for their children.

Social Dimension

Contemporary special education debates center around self-determination and empowerment, thus favoring the individual capacities of persons with disabilities in making decisions and being responsible for them. Great effort is currently made in developing policy and programs to help persons with disabilities take charge of their own lives. These efforts stress the individual capacity of the person with a disability. However, life transitions, such as the transition from school to adult life, include events that are beyond the capacity of the individual and take on a social dimension. The objective of this section is to explore this social dimension as it has been lived by the people in this study. The lives of people with disabilities are discussed against the great dynamics of changing people that American lives entail, particularly the image that different periods of life are associated with different people and the idea that one can have control over the people one is associating with, in part by controlling the place where one lives.

Three concepts are of importance: convoy, consociation, and mediation. *Convoy* or personal network (Plath, 1975, 1980; Kahn & Antonucci, 1980) is the structure within which social support is given and received. This structure is shaped by the interaction of situational factors and enduring properties of the person, which in turn determine in part the person's well-being and ability to perform successfully his or her life roles (Kahn and Antonucci, 1980, p. 269). While convoy is a structural concept, consociation and mediation are process concepts. *Consociation* refers to the personal, many-sided bonds with intimates that result from an engagement across long chains of interaction, implying depth in time and in attachment, and not confined merely to the execution of some particular set of role duties, the latter being typical of the relationship between associates (Plath, 1980). *Mediation* refers to

the social process of facilitating a life transition. It occurs in response to a social void and, if successful, results in social realignment. It will be argued that in order to understand the social dimension of a life transition, such as the transition to adult life, both consociation and mediation are important.

The life histories have provided several strong insights into the social aspects of life transitions. From Tina's transitions through life, it became clear that every life transition is marked by social realignment and results in a new social group. It was also pointed out how Tina's life transitions intersected with those of her adoptive mother and sister and her brother-in-law. These insights reflect the effects of consociation. The concept of mediation between different life periods was developed. These ideas are further explored here. In the life history of Sharon, the destructive nature of social relationships in her life was tied to her efforts to pass as normal and cover her disability. The continuous uncovering of this cloak explained the destructive nature of social relations in the lives of some persons with mental disabilities. These ideas were well developed by Edgerton (1993) and will not be further explored here.

Social time refers to the synchronization of seemingly individual transitions with those of other people, particular family members (Hareven, 1977, 1986). Several metaphors capture the idea that life transitions of different persons intersect and the development of different social groups through social realignment. Hareven (1980) proposes the "schools of fish" metaphor to express the interrelationships of individual transitions and changing family configurations. Alternatively, the idea of convoy has been used more frequently to express the same ideas (Plath, 1975; Kahn & Antonucci, 1980). More recently, it has been replaced with the term personal network. In the latter work, more attention has been given to the

nature of the membership and the mapping of the membership (Plath, 1980; Antonucci, 1986), while the former addresses more the interaction with historical forces (Hareven, 1979, 1980). Although both issues are relevant, the work on convoys more adequately suits the objectives of this study. The following discussions center on the nature of personal networks (or the configuration of the convoy) at the time of transition to adult life, the intersection of this life transition with the transition of family members, and the role of transition mediation.

So far, this discussion has focussed on how singular events become scripts and ultimately these scripts are transformed and negotiated within larger cultural schedules. The social dimension of the life course, however, has been largely ignored. "Human development has been thought of as a problem of biography and needs to be rethought as a problem of cobiography" (Plath, 1980, p. 288). In such an approach, the properties of a person are taken to be embedded in an ongoing convoy of human relationships.

In this study, the social network diagram has been used to map the contemporary configuration of each person's convoy (Antonucci, 1986). The instrument is a simple tool of four circles, one inner circle in which the word "you" is written, and three surrounding circles. The person is asked to list the important persons in his/her life according to emotional closeness. First, the person is asked to list those persons who are very close, then less close, and last, the least close. The researcher writes the names of the people in each of the corresponding circles. Table 3.5 summarizes the composition of convoys as they are portrayed by the people in the study.

There are a number of characteristics that are immediately apparent. The personal networks of the people in the study are relatively small overall. A larger membership can be observed in the first circle consisting mostly of family members and few friends. While in the

Table 3.5

Configuration of Transition Convoys

Persons	First Circle	Second Circle	Third Circle
Steve	Agency friend, roommate, girlfriend, three cousins, nephews, group home staff, mom, dad, sisters	Teachers, co-workers, 4 staff persons at work	Sister's boyfriend, Agency worker
Peter	Girlfriend and her parents, parents, relatives, agency client, apartment friend	Dog, two cats, hired man at the farm, apartment manager, agency supervisor, agency worker	Pigs, co-workers, agency boss, employer
Lori	Family (mom, dad, two brothers, grandmother)	Friends	Other relatives
Sharon	Mom and dad, neighbors children, boss		Day program supervisor
Brian	Mom, cousin, girlfriend, stepfather, brothers		
Timothy	Mom, stepfather, grandma, dad, twin-brother, sister, mother's friend	Nieces, nephews, uncles	Teachers, People who live far away
Tina	Boyfriend, sister, apartment, manager, three close friends	Two brothers, grandma, support worker	Agency friend
Mike	Roommate	Mother, stepfather	Supervisor at work
Joyce	Parents, two brothers, grandma, cousin and relatives	Church friends	Teachers, co-workers, classmates
Dennis	Mom and dad, girlfriend, boss, brothers and sister, grandma, aunt and uncles, teachers during the day	Friends at work	Friends
Justin	Key-club friend, sports fan at high school, three Church friends, three best buddy friends, mom, sister	Church friend	Friend who moved, former roommate, assistant principal who moved, couple who moved
Diane	Parents, roommate	Circle of friends	Co-workers

The persons who have a strong family involvement are Sharon, Brian, Lori, Joyce, and Timothy. Timothy is the most pertinent example of such a strong family convoy. Timothy and his mother form a tight bond, further supported by Timothy's stepfather, and to a lesser extent his father, twin brother, and sister. In negotiating the world, Timothy's mother is at the forefront. She cares about the needs of her son, is very concerned about his security, and negotiates with the agency to achieve accommodation. In her endeavors, she felt that she could not always follow the advice of the agency or comply with their usual way of doing business. As a result of strong family commitment, Timothy's transition is incomplete because it lacks the social dimension of a complete life transition. Timothy's mother is aware of this. She knows her son is spending whole evenings by himself but consoles herself by saying that "kids like Timothy" need a lot of time to get settled in, fix their meals, etc.

It is a somewhat startling finding that the young adults in the study who have similar support networks are not very independent. From Sharon's life history, it was found that social relationships are destructive, and her mother plays an important role in uncovering her cloak of competence. Brian is equally well supported in his family, and although he seems willing to move out of the house and live independently, the extra push from home is lacking. Lori also does not live independently. Her relationship with her mother is almost symbiotic: they work around each other's schedules and make them interdependent. Like Brian, the push to leave is not there. Joyce is somewhat an exception in this group. Supported by a strong sense of family, her dad helped her in identifying a program to study child care in a college which is run by their church. In all of these convoys, the relationship between mother and child is highly significant and deserves further study.

Agency-family convoys: Steve, Peter, and Diane. Whereas in family convoys the family assumes major responsibility for the life decisions of a family member with a mental disability, in agency-family and family-friend convoys, there is a clear break in responsibility. In these types of convoys, responsibility is shared with an adult agency or with friends. Steve, Peter, and Diane have agency-family convoys because in the course of the transition process, a good part of family responsibility was, willingly or not, surrendered to the agency. Interestingly, both Peter's and Diane's mothers went a long way in their professional careers learning about special education and adjusting their careers in that direction. In doing so, Diane's mother embraced many of the agency's goals. In the course of negotiating a situation with an adult agency, the scripts of the persons were written in terms that conform to usual agency practice as well as reflect the hierarchical status of the programs that are provided. Peter's entry into the agency and his quick movement up through several of the services of the agency reflect sharing the responsibilities among the agency, family and Peter.

Peter's life history is most pertinent for the purpose of illustrating an agency-family convoy. Peter was adopted at a young age. He moved from one adoptive family to another after the mother in the first family committed suicide and the father gave him up for adoption the next day. Peter's adoptive parents live on a hog farm. His mother is a special vocational coordinator, a career adjustment she made because of the mental disabilities of her son. In making the connections with an adult agency, Peter's mother does not refer as much as to the need for Peter to become independent or to contribute to society as to her and her husband's own rights for independence. As a professional, she was able to negotiate an apartment and a contract job for her 19-year-old son. She describes her involvement with the agency in terms of "them taking control over our son." However, because of the limited choices in the area

second circle several persons listed friends, Sharon and Brian listed no friends at all. Peter listed several pets in lieu of friends. Friends were mostly associated with work or church. In the third circle, the people listed were emotionally, and sometimes physically, distant. Some interpretation is possible about the interaction between the different circles. The first circle seems to be relatively constant, although people who are usually located in circle two or three may be invited into circle one. The most common movement seems to be from circle one to circle two: people who become unsympathetic or who physically move away.

Transition Convoys. Based on the membership of the different convoys, four different types can be distinguished: *family convoys, agency-family convoys, family-friend convoys,* and *friend convoys.* It is important to understand that these terms rather characterize an accent on the influence of one group of people: family, friends, or agency. These different types should not be interpreted as distinct from one another but rather as points on a continuum of possible convoys. These types of convoys partly explain how and why a particular adult script was developed. The convoys can be illustrated by an example of one individual who is most representative

for each type of convoy. Of importance is the nature of the relationships in each of these convoys. What is most interesting in this connection is how young adult life is shaped by the co-presence of important persons in the convoy. Relying on phenomenological theory, as developed by Schutz, Plath (1980) proposed the term consociation to indicate the depth in time and in attachment of human relationships. The focus of his approach is not on a Goffmanite presentation of self "but rather on the preservation of self in continuity and change across extended engagements" (p. 290). In the presentation of different types of convoys, the nature of consociation is explored as it relates to a major life transition and particularly how the nature of the transition to adult life intersects with life transitions of other individuals. Links are also drawn between the development of young adult scripts and the nature of these convoys and the outcomes in several life domains.

Family convoys: Sharon, Brian, Lori, Joyce, and Timothy. Family convoys are characterized by a strong sense of commitment of members of the family throughout the transition to adult life. Responsibility for support of the member of the family with a mental disability is essentially not surrendered although cooperation with an agency is not excluded. In the negotiation of an adult script for the person with the mental disability, the parents, usually spearheaded by the mother, take the initiative and are anxious to hold the process under control. They are demanding of agency for accommodation to specific needs and present themselves as "difficult clients." The persons with disabilities in these types of convoys typically do not fare as well in achieving independence as a result of their transition. Their transitions are incomplete in the sense that they do not live independently from their parents or they are not employed. Sometimes, these issues cannot even be discussed in contacts with agencies.

and an aversion to services in big cities, she finds that she needs to maintain contact with the same agency. The agency's control over their time schedules became apparent when the agency started a behavior modification program for Peter. In short, their son could not stay in his apartment if problems emerged at work. He was promptly sent back home the same day. His parents were required to pick up their son and bring him back a few days later, according to the program arrangements. Peter's mother found that these arrangements were made without their consultation and that the arrangements were an infraction of their rights.

In the course of negotiating an adult script for Peter, his placement in an apartment and in supported employment was a rather good result compared to Steve's, who was placed in a group home and in the sheltered workshops. In addition, soon after his entry into the agency world, Peter started a romantic relationship with another client, which gave him, at least in Steve's eyes, an ever higher status. Despite his rather good status, and as a result of his continuous evaluation of his situation with his girlfriend and her parents and his own parents, Peter became increasingly impatient with his situation. He wanted to become employed outside the agency and be married to his girlfriend. The agency was relatively uninvolved with these issues as they pertain to private matters, and most of smoothing out of these plans happened between Peter and his mother, who was unhappy that the agency did not take more initiative. The situation between Peter and his girlfriend ultimately exploded in quarrels and fighting which resulted in a broken window in Peter's apartment and police summoned. When Peter and his girlfriend broke up, the end of the love relationship pleased Peter's mother, and the whole situation turned to Peter's benefit as the agency quickly arranged an independent apartment in the community for him. In addition, his continuous

complaints about his first employment stimulated the agency to arrange a community job for Peter.

While the outcomes are rather positive for Peter, much of it is probably due to his own role in negotiating his situation with the agency. He complains endlessly about his situation and creates the sort of problems that attract the attention of the agency and lead them to take action. Such a role is to some extent also visible in Diane's behavior and the backing she receives from her parents. Steve, on the other hand, is much less successful in creating the kind of situations that move him towards greater independence. He also lacks the backing of his parents, a situation that deteriorated further after they divorced. To conclude, agency-family convoys are characterized by a surrendering of familial responsibility to the agency. However, the impact of the agency is often found to be inadequate, and the parents do not feel completely comfortable but trust that the outcomes for their son or daughter will be positive. The parents of these persons do take responsibility, especially when the agency does not want to become involved, such as in private matters. They also take responsibility during weekends and holidays. While these parents have launched an entry into the agency and into adult life, the expectation is that the agency takes over and that the person with mental disability relies on his/her own resources to further negotiate his life script. The family acts as a back-up but feels uncomfortable when they are actually asked to play that role.

Family-friend convoys: Dennis and Justin. Similar to agency-family convoys, the distinguishing characteristic of family-friend convoys is a clear break in responsibility and care of the person labeled disabled at the time of transition to adult life. The responsibility largely shifts from the parents to the person with a disability. It is subsequently shared with

friends. Dennis and Justin are examples of persons who operate within such convoys. Dennis's initiative toward independence was negatively stimulated when his father filed for bankruptcy and failed to provide emotional support. For Justin, his becoming independent has been strongly influenced by the fact that his father recently died and that his sister recently started college and no longer lives at home. For these reasons, Justin's mother preferred that he stay at home. Justin was employed in a sheltered workshop through an agency and had a background of special education. The relationships developed in these institutions took on a very personal character. From their account, people in these institutions became his friends and helped Justin on a personal level.

Interestingly, as a result of the absence of agency involvement, the label of mental disability may partly or totally disappear once the person leaves school. For Dennis, his assumption of major roles of independent worker, husband, and father will compensate for his academic deficiencies. For Justin, this is only partly true in his relations with friends in different clubs and at church. His association with sheltered work, however, becomes a burden when looking for work in the community. His friends do not seem to have the capacity of finding a job for him, and he becomes dependent on his agency. His Asian-American background plays out in two different ways. He is involved in training at a community college, is involved in many social activities, and is disciplined and directed by his mother. His mother's ethnicity and poor command of English, however, become a barrier to making connections in society.

Dennis's life history provides additional insights into the family-friend convoy. Dennis was still in school when he joined the study. As a special education student, he had moved between the labels of "severe learning disabilities" and "mental retardation." He seems

to be an excellent example of a "6-hour retarded" person because of his excellent functioning outside the classroom. At the age of 18, Dennis, who was still in school, had owned four trucks, worked every day from noon until midnight, and atteneded school the next morning. He also took on independent projects as an aid-mechanic during the weekends. He said he has no problems with money at all. Two months before graduation he was buying furniture for his house and after graduation, he planned to move into the house with his girlfriend, who was pregnant. He was offered a yearly contract from his friend, a farmer, as a hired worker and was offered a house in which to live. In Dennis's words:

> *This guy I work for now, [Eddie], I started working for him when I was 12. I worked for him until the summer of my 16th birthday. My 16th birthday was in April and I quit working for him like July. I then started working for a guy, he is a mud racer. I worked on a race car for two years. This [Eddie] came to me just this last summer and asked if I wanted to go to work for him. I said well, yeah, but I've got to make more money than I'm making now to go. He said OK. I kind of need to make more money and get more money and I was sick of traveling because I was gone every weekend. I mean I've been all over the world in two years, but I was sick of traveling, going everywhere. I wanted to be home for once. He offered me a better job, so I went with him. I used to work for him and he said I improved, so I started back working just this past summer. He said he'd give me a house, new truck, and I'd have to help him farm, and he'd set a salary for me [for the] year. He'd pay me so much a year for working and then the other time I could work for myself doing whatever I wanted.*

Dennis projected for his future that he would set aside $10,000 a year so that he could retire at the age of 50. He says:

Thirty years down the road, who says I can't kick back, relax and have all the fun I want when I'm older? That's what I'd rather have. My Dad is almost sixty years old and he's working every day away. He's defeating his purpose. He ain't getting nowhere, no head way. That's not what I want. When I'm about fifty I want to retire and take it easy the rest of my life. It finally dawned on me. That's what I want to be. When I'm about fifty, I want to go places and do things.

Dennis's working life was strongly influenced by his parents' life history particularly the bankruptcy of his father. When Dennis was still in grade school his family lost their farm and moved into a trailer on the periphery of town. His parents had set such a negative example that he wanted to be anything but them. He says about his parents:

I come home at night and watch my Mom and Dad sit around. It just makes me feel like, man, I don't want to be like that. I want to be further ahead. Every night, I think about what kind of bind are they in, or look they have to have this money or that money. I don't want to have money problems. I know that's not everything in life, but it's the biggest thing in life.

Dennis's father had also disappointed him at a young age when he once promised to take Dennis to a farm equipment show. His father changed his mind as he preferred to help out his neighbor, leaving Dennis with his expectations. Dennis remembered the event as a strong indicator that he could not rely on his father. In addition to his father, his brother also set a negative example for him. He had recently divorced and run into financial problems, and had asked Dennis to lend him money; Dennis refused. Dennis relies on his mother for moral and emotional support, but because of his busy schedule, he rarely sees her.

While his family, with the exception of his mother, had set for him a pervasive negative example, Dennis found substantial support in his community. He ventured at a very young age into meeting other people and getting jobs from them. He had a longstanding relationship with a mud-racer whom he helped in preparing his vehicles and with whom he traveled. He also had a good relationship with a farmer whom he helped during the busy season and with whom he gained experience in working inside the house during the winter when farm work was limited. Dennis was confident that these relationships could easily help him earn his living. He saw himself as partly employed, and partly doing independent jobs. It is certain that Dennis will disappear from his special education background and that nobody will perceive him as having a mental disability if he can keep that information to himself. His life will be directed by the network of friends-employers.

Friend convoys: Mike and Tina. In Tina's life history and development of an adult script, called a *liberated script*, much of her transition into adult life was determined by her independent living and a growing network of friends. The deterioration of her relationship with her sister and brother-in-law made it necessary to develop this network of friends, which became the most important source of support in Tina's life, although occasionally her apartment trainer, her co-workers, and her sister, provided her with support. One characteristic of friend convoys is the inadequacy of family or agency support. As in family-friend convoys, the development of independence based on the person's own resources and the lack of control and direction is obvious. In Tina's life history, her sister felt incapable of further directing Tina's life. The legal guardianship is the only remaining tool of control, which Tina anticipates severing by strengthening her relationship with her boyfriend.

Mike is another strong example of a person with a mental disability who operates within a friend convoy. Mike started to rely strongly on friends while still in school. His mother explained that Mike was once involved in a break-in at a school. His high school special education teacher related that she was successful in separating him from friends who were later arrested for using drugs. Mike's mother has always encouraged him to be independent and educated him that he was not different from anybody else. She promised herself that Mike at some point was going to be independent and out of her life. From his perspective, Mike questioned his mother's life style, as she frequently moved, mostly the result of getting acquainted with another man and subsequent marriage. He was proud to explain that almost immediately after graduating from high school, he told his mother that he was no longer going to live with her but with a friend. He has developed an almost symbiotic relationship with this person and refers to him as *"my roommate."* They financially support each other. Mike comments, *"When my friend is broke, I usually get my pay-check."* Mike pays for rent and contributes to buying groceries. Both like to watch horror films during their free time. Mike's job was a continuation of a job he started during high school as a janitor in the multi-function building of a church. Although the school is no longer responsible for supervising this job and an adult agency has taken over, Mike does not associate his identity with this agency. Rather, he detests their occasional follow-up visits and sees his relationship with his supervisor at work as more important.

To conclude, in family-friend and friend convoys, the impact of adult agencies is rather limited or non-existent for the identity of the person with a disability. The life foundations of persons who operate within these convoys reflects a good amount of

determination and enjoyment in becoming independent. However, lacking institutional support may account for potential changes in the lives of these persons.

Consociation: Intersecting Life Transitions. In the life transition of Tina, the intersections of life transitions were very clear and explain how her life evolved in different periods. This characteristic needs more systematic analysis as it evolves in the transition to adult life of the other persons with mental disabilities. Attention has been given to the impact of young adults' transitions on the related transition that members of their families also must make (Thorin & Irvin, 1992) and on the gradual change in the relationship between the person and his or her parents (Ferguson et al., 1993). From a life course approach, Hagestad (1991) proposes the concept of *countertransitions* to define such transitions. Similarly, Brotherson et al. (1986) pointed out that the changing self-identity of the person with a disability impacts the changing self-identity of family members. While this literature discusses how life transitions of convoy members influence each other in a somewhat causal manner, it does not discuss how the life transitions of different persons in one convoy co-occur and, as a result, how convoy members are being caught in the life transition of other members or how mutual adjustments are being made. In this connection, one could think of an *ecology of life transitions* in one convoy.

Table 3.6 summarizes how the transition to adult life of persons with mental disabilities intersected with transitions of important convoy members. The left part of Table 3.6 lists the individual in the first column and the transition component that intersected with a transition of a member in the convoy. In the right columns, the convoy member(s) and their life transitions are listed. Whether control in the relationship was legalized in a guardianship relation is also indicated. Steve's growing independence and need for continuing emotional

Table 3.6

Intersection of Life Transitions

Person	Transition component	Convoy member	Legal Control	Intersecting Transition
Steve	Overall emotional adjustment to independence	Parents Grandmother	None	Divorce Illness
Peter	Independence	Parents	None	Independence, Professional career
Lori	Dependence	Parents	None	Working Lives
Sharon	Dependence	Parents	Guardianship	Working Lives
Brian	Dependence	Parents	None	Working Lives
Timothy	Independent living	Mother	None	Marriage of mother
Tina	Independent living	Adoptive sister Brother-in-law	Guardianship	Marital problems Marital problems
Mike	Independent living	Mother Stepfather	Moral and emotional	Marriage
Joyce	Education Independent living	Parents	Moral and Emotional	Professional Careers
Dennis	Independent living Living with partner Work	Mother Father Girlfriend Friend farmer	Moral and emotional Negative reinforcement Partner relation Employer	None None Pregnant Support
Justin	Living at home	Father Mother Sister	None Directive and concerned None	Recent death New employment College student
Diane	Group home	Father Mother Brother Boyfriend	None	Professional career

support intersected with the divorce of his parents, a situation from which he suffered emotionally. His distance from his father became greater, and he adjusted to acceptance of his father's new partner. In addition, his need for emotional support was further harmed by the fact that his mother became preoccupied with her own ailing mother. In Peter's life history, his parents fully anticipated that Peter's eventual independence would eventually result in their own independence. Peter's initial problems at work, which caused the agency to send him temporarily back home, were not appreciated by his parents. Their intervention with Peter and with the agency was geared to returning to the path of mutual greater independence. Lori's continuing dependence upon her parents, both in terms of living arrangements and in financial terms, co-occurs with the working lives of her parents. She is not stimulated to live independently or to replace her volunteer job with a real job. Instead, a symbiotic relationship between mother and daughter is cultivated. According to Lori's brother, it will take a significant life transition of his parents, namely retirement, to push Lori into a greater independence. A similar dependent relationship exists for Sharon, who believes this will be maintained until her parents die. Sharon's parents have made few provisions to increase Sharon's independence, based on a strong belief in her incompetence and the need to unveil her cloak of competence at all times. Because of the lack of a biological relationship and a perceived need for Sharon's protection, Sharon's parents have become her legal guardians even though she is over 18. Brian's need for independent living has not been favorably met by his parents, whose working lives have not stimulated his leaving home. The idea is especially resisted if it means that he will need their continued support in another living place. Timothy's independent living was connected to the beginning of his community employment. It co-occurred with his mother's marriage and the moving in of his stepfather and his

children. Timothy was happy to leave and comments that "the house was kind of full." Timothy's physical transition was not followed by social realignment, as his mother and stepfather maintain prominent roles. Both became satellites of each other. Tina's intersections have been largely discussed previously. Her guardianship relation with her sister is the only tie that needs to be broken to make Tina fully independent. Mike's move from his mother's house co-occurred with his mother's new marriage. His independence and his mother's marriage were well timed. Joyce is the only person with mental disabilities for whom an education beyond high school is anticipated. Both her parents are professional nurses, and her father is a Ph.D. candidate. This professional orientation has shaped the expectations that the parents developed for their daughter. Dennis's vigorous anticipation of independence have been shaped by the members of his convoy, although largely in negative terms. His social realignments do not concern his parents as much as a strengthening of his friend-employer relations and the development of his own nuclear family. Justin is a good example of how the development of independent living can be put on hold temporarily because of other life transitions in the household. The recent death of Justin's father and his sister's departure for college inhibited Justin from leaving. In other areas, however, such as recreation and transportation, Justin's independence is strongly stimulated.

The transition to adult life is for any person a complex set of events that involve planning and in which a script is developed and mediated by the cultural schedules in a society. For the person with a disability, these cultural schedules are transformed as a result of the additional institutional context in which an adult life is negotiated. In addition, as Stone (1991) eloquently argues, such life transitions are mediated by families, or as argued, in a broader sense, by the configuration and dynamics of the convoy in which a person operates.

The intersection of transitions of members in a convoy leads ideally to a mutual adjustment. In addition, the knowledge of intersection can produce a sense of security and protection. For example, the knowledge that Justin had of his convoy members, his dad, sister, and mom, created a sense that this was not the right time for him to leave the house and that he should stay home for the time being. In other life histories, the knowledge of intersection acts as a stimulant for independence. Such was the case for Timothy, Tina, and Mike. The transitions in their mothers' lives acted as stimulants for greater independence. In other life histories, the absence of intersection felt uncomfortable. Such was the case for Lori, whose brother anticipated that an intersection needed to be created for Lori to become more independent.

Transition Mediation. Although the structural concept of convoy and the process of consociation are important for understanding the nature of life transitions, the discussion must be complemented by the process of mediation. Mediation accounts for the changing configuration of convoys over time and for the changing nature of the individual life course in different time periods. Tina's successful transition in living and work was mediated by both members of her convoy and persons outside of it. It is characteristic of mediative action that it is temporary, and in this sense, it is radically different from consociation. Mediation does not belong in the realm of everyday activity. On the contrary, it is action that reaches out of the ordinary into the new. Mediation must also be distinguished from *coping*, which refers to the management of a difficult situation, indicating the stresses that go along with such a situation. In contrast, *mediation* concerns the creative power of individuals to change situations and change the configurations of their convoys, that is, to change the people in their lives. Mediation refers to the power of driving a wedge in a wall of structure, or, in other words, to subvert an ecological balance. Mediation is an important component of the

transition process. The mediating force of different stakeholders in the process depend on knowledge, professional background, experience, and personality.

In the lives of persons with disabilities, parents can only partly rely on their own experience of adult life because they usually lack the experience of being disabled themselves. When their son or daughter becomes an adult, they generally do not know what is available. In research with parents of children with disabilities, a consistent finding was that parents were not merely uncertain about their rights, but were also generally ignorant of just what ranges of services might be available to them and their children at any particular time (Hughes & May, 1988). This lack of knowledge, then, makes mediative action imperative. It is part of the responsibility parents have "to launch and let go."

In the life histories of the persons in this study, transition mediators include the person with the disability, the parent(s), professionals, and friends. The extent of each individual's mediative action is summarized in Table 3.7. Steve has not been very successful in mediating his situation, relying on his own resources. Rather, he has opted for making trouble with other agency clients, sometimes out of jealousy, and he has preferred to have fun rather than diligently to work and to comply with the rules of his agency. His parents, especially his mother, who initially contacted the agency, were so impressed with the agency's programs that they chose not to further negotiate Steve's situation. The adult agency has provided Steve with work and group home living. As mediation from the parents side was weak, the agency functioned on its own terms. Stone (1991) has noted that professionals mediate within an allocative context, meaning that experts operate under quotas, either implicitly or explicitly. She further described professionals as gatekeepers, because there is a limited number of slots to assign. Steve presented the contacts of his mother as successful

Table 3.7

Transition Mediators and Mediative Action

Person	Transition mediators and mediative action			
	Individual actions	Family	Adult Agency	Friend
Steve	Making trouble, being jealous, having fun	Contact with agency, seasonal transitions	Living: moving; Work: sheltered workshop Behavior programs	None
Peter	Demanding change	Contact, negotiation	Living arrangement	None
Lori	Adjustment in the home and at work, small talk	Community network	Information	None
Sharon	Inventing reality Submissive to mother	Initiating, Controlling communication with agency, monitoring Sharon 's schedules	Work placement Providing Transportation	None
Brian	Explore living with father, express wish to move out	Contact agency and "work with them"	Training, recreation	None
Timothy	Spanning with his mother	Being the satellite: negotiate social security, living, community work, building accommodation, transportation accommodation	Living arrangement, security training, apartment training	Backup
Tina	Flexible adjustment, hard work, communicating	Living independently in an apartment	Community employment	Model for guardianship
Mike	Negotiate independent living	Emotional reaction toward agency; Push for independence toward Mile	Minimal supervision of work, job arranged by school	Living; Recreation, Transportation
Joyce	Making choice of interest in working with children	Strong family ethics	None	None
Dennis	Negotiate independent living, work, partner relation	Negative model	None	Employment
Justin	Adjust and rebel to convoy ecology	Asking professionals for special attention	Sheltered employment	Company
Diane	Living together with other people	Facilitate access to a larger audience	Community employment, living	None

because, in Steve's words: *"Sure enough, they said, 'we have a group home for Steve.'"* The adult agency became the main structure that will mediate all main issues in Steve's life. Steve's parents provide intermittent support, especially during weekends and holidays.

Peter has much more success in mediating for himself by demanding change, not always in a very friendly way, but he is ultimately effective. He has also created problems of such a magnitude that the agency was forced to alter his situation. In a very short time, Peter moved from a supervised apartment to a community apartment and from sheltered work to community work, much as the result of his own restlessness and initiative. As a professional, Peter's mother has sufficient background knowledge to be able to negotiate and mediate a superior entry situation into the agency world. The agency has acted more rapidly than it does with other clients because of these mediative actions and as a result, Peter's has achieved maximum independence.

Lori has not ventured into a lot of mediative action because her home has been accommodating enough. After Lori was fired from one job, which an agency organized, Lori's mother relied on her own community resources to arrange a volunteer job in their own community. The agency as a resource for greater independence was put on hold; all it could do was provide information.

In mediating her situation, Sharon has tried to cover her deficits, experiencing again and again that they would be uncovered. She would try harder and invent the knowledge she did not have. The effects of the cover could be successful in short encounters, but they would be destructive in longer relations. Sharon's mother's understanding of her daughter's incompetence and her efforts to remediate it led her to protect the outside world from her daughter and to engage in bonds with outsiders to manage the situation, much to Sharon's

frustration. The agency operated within the demands of the mother; it arranged for employment and transportation and but was cut short concerning plans related to independent living. Sharon's mother envisaged a group home as the only possibility and did not wish to consider this option or the possibility of other options.

Brian has not been very resourceful in mediating his situation. He developed the idea of moving out of the house, probably influenced by discussions with professionals. He considered living with his father and travelled to spend his summer vacation in his home. Brian's mother initiated contact with a local agency after Brian's file got lost. Her attitude is consistent with what Hughes and May described as "controlled by the hand of fate and being dependent on some remote, and not always identifiable authority" (1988, p. 101). Once an agency was contacted, their mediative actions with Brian were characterized largely by inertia.

Timothy has thoroughly enjoyed his move out of the home and his community job. It is not the outcome of mediation on his own but of teaming together with his mother. Because he uses a wheelchair, having rather severe cerebral palsy, Timothy's relative immobility has encouraged her to accommodate his needs. The agency had to operate within the priorities set forth by the mother-Timothy team. In addition, friends had been organized as backup should the team fail.

In Tina's life history, the importance of the timing and temporality of mediative action becomes clear. Tina's sister reached out at the time that Tina was graduating from school, and her marital problems caught Tina. She followed through with the arrangement and found the resources to have Tina buy her furniture, move, and get settled in an apartment, after which her mediative action ended. The agency mediated a community job, with input from Tina, in

a retail store, after which its mediative action ended. The mediative impact of her friends now becomes more important, especially her boyfriend's. It becomes a model of reversing the legal remains of a longstanding relationship with her adoptive sister. The agency, in the person of her apartment trainer, may be called to mediate this transition.

Mike has been very resourceful in mediating his own transition to independent living. While he was following a friend to whom he had lent money, he met a person who subsequently became his roommate. His mother had set the stage throughout his education by stressing his worth as a person. Agency and school professionals remembered her for emotionally acting out during meetings. His school arranged a janitor job for him in a school, which turned into a regular job upon his graduation. As Mike intends to travel and relocate at some point in his life, he may completely disappear from the professional world of disability service.

Joyce has not been very successful in mediating her own situation. As a member of her family's fundamentalist Christian church she has formed strong moral opinions; however, her classmates have been alienated rather than inspired by this. Her parents have mediated an arrangement for continuing education in a community college run by their church despite the advice of the school that this might be too difficult for Joyce. Dennis has probably been the strongest mediator of his own life, motivated by the negative model of his parents. He has been extremely resourceful in designing his own life. His employers became his friends, and his friends his employers. Justin has not been that resourceful, nor has his mother been able to mobilize the resources that could provide Justin with a good future. His placement by an agency in sheltered employment is inappropriate in view of his capabilities. However, the

agency has not been able to manage an alternative. Justin's mother has resorted to waiting for their solution.

Diane has successfully mediated several moves in different independent living arrangements. She currently shares an apartment with a roommate. She had found living in a group home short of privacy but also found it hard to manage the loneliness of an apartment. In the new arrangement, she struggles to find a good balance in which her social needs and those of her roommate are met.

Transition Assessment for Mentorship

A strategy is necessary to assess transition as life transition. Based on ethnographic life history work, a basic model of the life transitions of a person with mild mental retardation is presented. This model will be applied toward the development of key questions in an assessment of transition as life transition, such as: What are the critical events in the person's life? What adult script is anticipated? How can the person's convoy be conceptualized? Who are the person's transition mediators? The planning, development, and management of supports is linked to an assessment of transition as life transition.

IEP practice must be reformed resulting from the insights of the dynamics of life transitions. Specifically, the IEP process can only be a component of mentorship for transition. Effective mentorship includes (1) a developed relationship that amounts to the collection of life history information; (2) an analysis of adult scripts and the social network as part of transition assessment; (3) a sorting process in which the mediative capacity of the person with a disability and social network are assessed; (4) a problem-solving process to identify sources and assign responsibility in the development of mediative capacity; and (5) the provision of technical information. The current IEP process can play a role in enhancing

mentorship for transition when it is applied as the main vehicle for the problemsolving process for students and their social networks who lack mediative capacity. Within this approach, the IEP process should be elaborated for students who need assistance and should be diminished for students whose mediative capacity is determined to be adequate. The IEP process should be reformed to meet these goals.

Two requirements are necessary to develop an effective approach. First, transition from school to adult life must be understood as a life transition and an approach must be developed to meet this goal. Insight into life transitions and insights into the way the student experiences this process are the basic requirements. Insight into life transition can be acquired through the use of life history, and insight into the student through a development of a mentorship relationship. In using a life course approach, a holistic picture can be developed, accounting for an understanding of life transition and of the way a particular student and social network experience this transition.

CHAPTER IV

STUDYING TRANSITION THROUGH LIFE HISTORIES

Tina's life history is presented in narrative style in chapter III and included there to provide a basis for understanding the life history method, life domains, script analysis, critical event analysis, and convoy analysis. Her life history and the subsequent analyses of it are used as a comparative tool for understanding the variety of possible scripts, events, convoys, and mediative strategies employed by several of the subjects of this study.

This chapter includes parts of the life histories of eight members of the research project. For purposes of consistency within the text, Tina's life history was written from the perspective of an absent researcher; references to the author and his personal experience with Tina were excluded. This style of writing does not communicate the interpersonal and dialectic nature of the narrative produced. In the following life histories, the first-person structure, the reflections of the author, and the author's personal experience with the subject have been retained. The inclusion of this information is important, if not for greater understanding of the life history itself, then certainly for an understanding of the nature of mediation and mentorship.

As discussed in chapter III, the life histories collected are always incomplete and are not revealed immediately, but are accumulated gradually. The life histories presented here are the product of the subjects with mental retardation, their significant others, agency and school personnel, and the researchers. The researchers' role in producing the life history is one of selecting relevant events, statements, and perspectives, and presenting these fragments in a

manner that is concise yet reflects the intricacies of the lives represented. The complexity of the subject requires selectivity, and the writer is faced with decisions that will affect understanding. It also leads to further puzzlement, and an invitation to continue investigation because the phenomena cannot be completely revealed. In the following life histories, the reader is invited to join in the process of revealing and understanding and in the continuation of investigation of life histories.

Life histories increase the knowledge of the process and quality of a life transition. As a researcher, I attempt to illuminate a phenomenon that is partly in the dark. In John Benville's words, my attempts are at "making things go still so that they start to glaze," and hope that as a writer, the phenomenon of life transition will just do that. A 1952 painting by René Magritte entitled "The Dominion of Light" may help to clarify further this objective. In this painting, a row of houses and trees, seen from the street, is partly illuminated by a pillar. The rather dark-night scene is shown in contrast to a bright day sky. As a researcher of lives, I take myself to be the pillar in Magritte's painting, illuminating part of the scene that a life transition is. As an author, I am present in my account, but I leave it to you as a reader to take account of my presence or to ignore it and concentrate on increasing your insight into life transitions. Magritte's painting is complete because the light that comes from the sky and from inside one of the houses simulates the help that others offer in a research effort of elucidating a phenomenon.

In the attempt to explain, a writer is selective, sometimes deliberately and sometimes concidentally. All contribute to the power of the text. Here the selection process must be clarified before the eight life histories are presented. I have been selective in a particular use of the life history method and in choosing eight of twelve subjects. I have also been selective

by focusing on one life transition, the transition from school to adult life, and by presenting only a fraction of the diversity of life events.

Tina's life history demonstrated the basic structure of life transitions and particularly the importance of critical events and the role of mediators in transition. The clarity of Tina's transition and life history stands in contrast to the following life histories, which present very different situations. Thus, further study of the life transitions of persons with mental retardation may be facilitated by an increasing understanding that starts in Tina's life history and continues to reveal aspects of life transition. For instance, I chose to portray Steve's life history because I worked intensively with him and have been puzzled for a long time by his particular transition and accompanying set of problems. Whereas Tina's life history held significant explanatory power for understanding life transitions, Steve's life history is a mirror for continued puzzlement by the complexity of life transitions.

In Steve's life history, I was struck by the way his voice is made up of other's voices, and that in his transition to adult life, he was caught between several voices. Steve's life history answers to my concern of voice and the presence of significant others in a life transition. The importance of voice is reflected in the juxtaposition of different perspectives that I use in writing life histories. By presenting them without integration, I intend to convey the emotional confusion that goes along with being caught between different voices. I also suggest that it is important to recognize these voices; it is perhaps even more important to recognize the limitations of Steve's mediators.

Sharon and Brian's life histories are situated next because in a sense they clarify the markers of the phenomenon of life transition that I identified in Tina's life history. Sharon and Brian's transitions demonstrate what one can learn from life histories that do not reflect

successful completion of life transition. In Sharon's life history, the dominance of relationships is the most prominent theme that explains the development of adult life. Edgerton's (1993) "cloak of competence" idea explains well how relationships develop and become self-destructive. Last, in the life history of Brian, I explore the importance of expanding space as another important marker of life transitions. Brian gets stuck in his transition to adult life because the physical transitions, such as living in his own apartment, working in a distinct place, and independent mobility are postponed. American culture has important images that portray expanding one's life space, for example in the phrase, "going West." However, for Brian, "space" as a marker of life transitions is limited to "places to go." "Pressed mobility" has not caught up yet with Brian. His mother says: "We keep him going," thus indicating a lack of speed and a lack of meaning in life. I have used a classical narrative style but took into account the impact of one significant event in Brian's transition, namely that he wanted to move from Illinois to Hawaii and did not succeed.

In addition to the life histories of persons who were interviewed while in transition, the life histories of several individuals from two additional groups, Pre-transition and Post-transition, have been included. The life histories of Dennis and Joyce are important for what they disclose of transition planning and for showing how one who is labeled disabled in school may cease to be disabled once he or she leaves schol. The life histories of Diane and Karen, on the other hand, demonstrate the ongoing nature of transitions that begin once a person exits high school and continue to evolve.

In Transition

Steve

Steve: Caught in Multiple Perspectives. In portraying the transition to adulthood for Steve (and later for Brian), I worked out three central perspectives on his transition, which represent different voices. These perspectives reflect the ideas of different stake-holders who are involved in the negotiation of Steve's transition. As I listened to these different voices, I became aware of multiple realities. People omit and add information to their perspective and in the way they interpret their involvement in a life transition.

The different perspectives also evolved to a great extent from the way the research developed. I was initially mostly interested in learning about the insider's knowledge of a life transition (i.e., how the person with mental retardation experienced the transition). However, that knowledge became relevant only when it was contrasted with the knowledge that others developed from their involvement in the transition. This evolved into an ethically sound principle of asking the person to identify a person in his/her family and in the school or adult agency with whom I could also talk. I would have found it a distortion of a trusting relationship to gain information about the person without having first consulted that person.

The first description portrays an insider's perspective. It is based on what Steve told me during our meetings and visits in the course of approximately one year. My reconstruction of Steve's voice is based on his visits to my home, which were preceded or followed by formal interviews in my office, and on visits with him at his group home and his mother's home. On each occasion, I called to schedule our meeting and picked him up from his group home. From the conversations at the group home, in the car, at the dinner table, and during more formal interviews, I have created his perspective.

The other perspectives are additional and should be read as such. They are intended to compare or to contrast with Steve's perspective. I chose to arrange three of these perspectives, using different type faces to distinguish them in an effort to represent the complexity of various perspectives in reality. The various perspectives can sometimes be read as different scripts on the transition to adulthood (i.e., representations on how a life has been lived, or should be lived). In all of these perspectives, I have arranged the text with subheadings on salient topics that are relevant to his transition to adult life. In order to protect privacy, all names have been changed.

Steve's Voice: Moving Between Homes. When Steve graduated from high school three years ago, he moved from his parent's home to a group home and is now living in his second group home. He anticipates living in this second group home for a long time but hopes eventually to live by himself in an apartment.

During the last year of school, agency personnel would call Steve to see if he could come to town for a tour. He would go with his mother and father so that he could show them what jobs he could do, and they could show what jobs they were working on. He was introduced to living at a group home by staying there overnight.

> *Then, we got word that they had a house open for me. So, I stayed with my friends and then Mom came and got me the next morning and took me home. I kept doing that. I liked doing that. The house manager called me mostly in the afternoon and asked my Mom and Dad if they would bring me down. I packed my suitcase, my [model] cars and clothes, and stayed overnight with them. We ate dinner, watched TV, talked, stayed around, played cards and went to bed. The next morning, they called Mom, and told Mom to come down and get me. I like doing that. I miss doing it again.*

When Steve moved from the first group home to the second, two people from the agency came to help him move. There was already another person in his new room. Steve remembers that this person was teasing him, saying to the staff person, "*I got to be with that stuck-up person? Oh brother, I got to sleep with this person?*" The staff person replied: "*Yeah, you do. You got to sleep with Steve. You got to be nice with the new person.*"

Steve interprets his moves from one place to the other as a result of his own behavior. Remembering his move away from his parents' home, he said, "*Actually, my Mom and Dad wanted me to move over there because they don't want me to get into too many fights where I lived. So, I decided it's best for me to move. I got my stuff packed and moved over there.*"

Again, from his perspective, fights between him and other persons at the group home made his agency decide to move him to another group home. Steve told me he likes to fight with his roommate in the group home. However, it is difficult to tell whether these fights are aggressive. Other advantages of the move, such as a better bus schedule, were of less importance, although he sometimes used this explanation.

The group home is the intermediate step between his parent's home and life on his own in a small apartment. As the ultimate goal, it still seems far away. He reflects upon his own behavior as the major barrier for reaching the goal. Apart from getting into fights at the group home, he likes to trade clothes with other group home members. He thinks it is fun to wear other people's clothes, but the staff does not think so. According to Steve, other fellow group home people say that they do not need the clothes anymore, and that Steve could wear them. Steve tries to resist accepting the clothes because he would be fined for them by the group home staff. His housemates say, *"OK, give 'em back to me and I'll hold them for ya*

until I see you at work." When the staff find that he has other people's clothes, *"They always say, 'Steve, take it off. Change into the clothes that are yours.'"* The agency staff also developed a program, called the "clothing check program." Steve says, *"They check closets around 9:00 o'clock to see if they can find clothes that do not belong to me. When they find clothes, I get fined for 25¢, 10¢, or $1.00 or sometimes $2.00. Some staff are strict and the fines are really hurting me and that it may take a long time before I will be on my own."*

Steve's Voice: The School-to-Work Transition. Steve went to two different high schools recently. Central in his experience were the fights he got into with other children. The fights were due to some kids that started not to like him. These children became intolerant of Steve's being late for classes and forgetting his homework. *"They were playing around me telling me I better get my homework done or if I don't I'll be in trouble."*

In both schools, *"Some kids were picking on me, hitting on me and cussing me out and saying stuff like 'your Mom's like...', and I did not like that. They grab my stuff and steal it, saying 'you're not going to get it back until you be nice.' I said 'No, I'm not going to be nice to you.' 'So, then you're not going to get your stuff back.' So, it became total chaos with these guys."*

Steve had two ways of handling the situation. One was to tell the principal, who would say *"Just don't worry about it. Just walk away from them. Just ignore them when you go by them again."* Steve would reply, *"I can't ignore them and if I do they are gonna start hitting and they were. I have to defend myself but I don't want to get in trouble for it, get suspended from school."* Tell the principal was advice that he took from three of his best friends at school. Steve thought it was the right way to handle this, but it did not solve the situation. The other way out was getting into a fight:

I like hit them. I'd say I was going to get my cousin after them. They say "Oh, your cousin cannot do nothing to me." I said, "Oh, yes she can." They kept saying "No, she can't" and I kept saying "Yes, she can." I got mad, so I just let them have it and I just decked them a good one and that was that. No more saying my cousin could hit them when I knew I could hit them myself. The teacher catches me and the principal comes in and catches me and wow, that was that.

The solution of getting into a fight was the solution that Steve was somewhat proud of as he tells me the story that he can defend himself. It goes back to the advice of one of his cousins, someone he visits each time he goes back home. Steve acts theatrically when he relates his conversations with her. Steve acts her speaking to him like this:

"Cousin Steve. Cousin Steve, do you want some honest advice from me?" She goes, "Do you want the bad advice or the good advice." I say, "Give me the good advice." She says, "If anyone is bothering you, deck them a good one, before they can give you one. And do it somewhere, where they can't see you. Don't do it in front of everyone."

Steve enjoys telling me this story, but he knows its limits. He knows that he could get suspended and he knows he should not hit his friends, because if he did, they would not like him anymore.

Steve stresses the support of his teacher and of the principal. His teacher would get mad when other children came up to Steve to call him names and she would tell the principal about it. The principal came into the classroom to talk with the children and *"He would stand in the hallway making sure people don't call me names when I go for my next class. He would*

stand there and say, 'Hey guys, do not pick on Steve.'" But despite this support, Steve asserts that they kept doing it. They kept on calling him names, like *"baby"* and *"jerk"*; they even wrote these names in his yearbook. At times, he would go to the principal, and they would be right there outside waiting for him.

Steve remembers his graduation party vividly. He tells me how he left the school, and his parents and sisters found him in tears because he would miss all his friends. They would comfort him, saying that he should not start crying because he would see his friends next time he comes home. They took him home and had a graduation party with his grandmas, his aunt who made a graduation cake, and other relatives, all who gave him presents. He remembers some of the gifts he received from them.

Steve is well aware of some of the meetings that were organized in his schools to which his parents were invited. His interpretation of these meetings focuses again around his behavior. At the meeting, the teacher would tell his parents about the problems he was having at school. His mother would already know about the problems. She would already have given the advice to Steve to try to ignore other children and refrain from saying anything that could make them mad. When the teachers would ask his mother whether Steve had similar problems with other kids, his mother would say that *"to her knowledge she did not think he had."* Both the teacher and the parents would repeat their advice at the meeting, saying that if the kids came to him, he should just ignore it, that if they said anything about his family, he should not say anything to them, and not say that he would get them or that his cousin would get them. Steve would just say that he would not say anything.

However, when I asked him whether ignoring was the right thing to do, he was doubtful. *"I am supposed to defend myself. That's what my cousin has told me, that I should defend myself once these kids treat me mean."*

Steve's Voice: Work. Steve packages foodstuffs in the sheltered workshop of his agency. He does not like his employment very much because it is too noisy. He feels he needs to take too much responsibility, along with the workshop staff, to clean up when other workers drop foodstuffs. Steve likes the workshop staff, but does not like it when he or other people get yelled at when they let things fall on the floor. He says that people get sent home, or sent to another section of the work place, when they let things fall on the floor. He helps the workshop staff on one of the lines and, together with his girlfriend, they help remind other people that they should not drop things on the floor or they will pay the consequences.

Steve's Voice: Friends. Steve recognizes some people as his friends. He certainly considers his roommate at the group home and his work mate, Peter, as his friends. His relationships with these people is portrayed as I have heard it told from Steve's perspective.

The person at the group home to whom Steve is closest is his roommate. His roommate reminds Steve to do things and to get ready for the next thing. One conversation with his roommate went like this:

Roommate: *If your friend Pat is coming, you better get up there and ready to go. Get your bath, shave, comb your hair, brush your teeth, get your clothes on, and get ready.*

Steve: *Eye, eye captain O dad.*

Steve compares his roommate to his father, for helping him "to keep in line." However, he also relates to Peter as a brother which provides a different context.

Steve's relationship with his friend Peter is over. I followed some of its development between Halloween and Christmas, until Steve decided that he no longer needed Peter as a friend. At first, Steve described his friend as "blond hair, blue eyes, tight jeans, t-shirt," someone that he was looking up to. Steve knew Peter because Peter was at Steve's cousins' school, and his mother, who works in special education, also knows Peter. At times, Steve gets concerned about Peter's medical condition. He also became very interested in the development of Peter's relationship with a girl. His concerns and interests evolve into fights. For example, one day Steve stated in front of Peter and his girlfriend that she must find him very attractive. The girlfriend stood up and walked away. Peter then said to Steve, *"Thank you for doing this to my girlfriend"* and walked away.

Such events may eventually lead to fights with mostly verbal abuse, slamming doors and locking each other out. After a while, one or the other would apologize. Steve says,

> *Now we are apologizing for the fights we had. Every single time we get into a fight on the phone he calls me and says, "Friend, I'm sorry for what I've been putting you through." I said, "Don't worry about it." I turn around and apologize to him and he says, "Don't worry about it, just let it pass by." So, that's what we do.*

This kind of behavior is closely observed by agency staff, and it becomes the strongest evidence for proving Steve's immaturity and denying him permission to move along in the agency to the next step, be it more independent work or more independent living. His agency worker described the behavior at the level of junior high and concluded that Steve

would not be ready to engage in any more independent activity. Where Steve's behavior becomes intolerable, the agency develops programs; meanwhile an attitude of "waiting" is developed (i.e., until "Steve is ready").

On some other occasions, I have been able to observe the strong relationships between Peter and Steve. I had to agree with the interpretation of one group home worker when, during a summer picnic, I observed that Steve was rather jealous of Peter. The group home worker interpreted Steve's behavior as a result of his position in the adult agency. As Peter was ahead of Steve in almost every aspect of life, such as better work, more independent living, a steady relationship with a girlfriend, Peter became a role model for Steve. However, that Peter was also younger than Steve and that he came into the organization at a later time than Steve made it impossible for Steve to follow him.

Family Transitions. Steve's family consists of his mother, father, two sisters, grandparents, aunts and uncles, and cousins. Steve is upset about his parents' divorce last year. He resented the idea that he would have to buy several Christmas presents and give them to his mother and father at different times. Although he likes his father, he feels more attached to his mother. His mother encourages him to spend more time with his father, but Steve feels there is not enough time to do so.

Recently, his mother became very occupied with her own ailing mother, 67, who had been hospitalized. Steve visited his grandmother but feels he receives less attention from his mother when he visits her. When asking to categorize people that are important in his life according to emotional closeness, he felt unable to categorize his grandparents.

Steve becomes worried at times about the lives of his sisters. His older sister Betty lives with her boyfriend, and Betty has two children. She works in a gas station. Her former

boyfriend used to come to ask for his son. Steve's sister did not like some of his behavior. Steve's younger sister Lisa is a teacher and a bartender. According to Steve, Lisa and her boyfriend were supposed to get married sometime, but they had gotten into a fight recently. Steve had suggested to his sister that she call him so that he could call the police if necessary.

Consequently, the significance of these family transitions is that Steve's transition to adult life is embedded in an ecology of transitions in his family. The divorce of his parents and his grandmother's illness are important transitions that greatly affect Steve's mother and Steve indirectly. Steve's case coordinator noted that as these events developed at home, Steve had a more difficult time maintaining and developing his own independence.

Steve's Mother's Voice.. I visited Steve's mother at her home when I drove Steve there for the Christmas holidays. When I talked with her, I learned that her perspective of the move between schools and between home and living in the group home is very different from Steve's perspective.

She explained that Steve had to be moved from one school to another, not because of Steve's problems with other children as Steve explained it, but simply because there were too many special education children in the one school, as allowed by the law. The school had therefore contacted another high school that had no special education students and consequently very little special education experience, but which had to take special education students if they applied for enrollment. Because the new high school had very little experience with special education students, Steve's parents felt alienated. Rather than trying to motivate Steve to do his best, their objective became to obtain the necessary study credit so that Steve could graduate, an achievement of which Steve's mother said she's proud. Remembering his graduation party, she said it was good, but not as big as she wanted it to be.

When Steve was moving out of his parents' house, it was difficult, as for any child. However, she found that she had done the right thing; as she was not going to be there all the time for Steve, people live and die, and that Steve had to be on his own. She and her husband had been to visit the agency and were impressed with their programs.

In general, she found that Steve had been good. She found it was a good thing that he got out of trouble in the first group home and moved to an all-male group home so that they could do "guy-things" together. She also found that Steve still had to grow in a lot of areas and that he would have to live in a group home for some time before he could be on his own. She could not imagine that Steve would drive his own car since he tried to pass the driving test some time ago and did not succeed.

Steve's mother was well aware that her divorce was very upsetting for him. She described her divorce after 29 years of marriage as hard to accept but friendly; it had resulted from the fact that her husband had found someone else. She continued to talk with her ex-husband and they continued to work in the same company. Talking about Steve's father, she found that he was a good father, but perhaps a little overprotective and always anxious about Steve's security. She seemed to want Steve spend more time with his father but added that they never had a very close relationship, perhaps because he had been overprotective.

The Agency's Voice: Steve's File in June 1992. Steve was born September 23, 1971. He has mild mental retardation. His mother is Cheryl Green and his father is Jeff Green. His race is Caucasian. He scores 55 on the WISC-R test and 69 on the Stanford-Binet. His interests/hobbies are attending the Lutheran church, model car kits, music, dancing, bowling, and sports. He enjoys watching TV, cartoons and sports, especially watching the Cubs and the Bears. His siblings are Lisa, 23 years old, and Betty (no age mentioned).

There are no jobs that he would not like to do. He would like a job in which he could move around. He would like to work as a janitor after he completes school. He needs more experience with occupational and career awareness, for example, with identifying jobs and knowing which jobs are available. Steve's knowledge of work performance behavior is weak. He could not answer why people get fired, what an employer would like, or what to do if you are absent or late for work.

His strengths are in basic concepts, functional signs, and public services. Weaknesses are in areas such as domestic skills, health and safety, time, money and measurement. His deficits in employment are in adaptive behavior required for independent functioning. Other weaknesses include cognitive processes; coordination of movement using fingers, hands, and wrist; and coordination and balance using arms, shoulders, back, and abdomen. He has been in special education since he was 6 years old. He has a short attention span. He has a lazy eye. He comes from a good home with concerned and caring parents. He was in early childhood classes in 1976-77 and was categorized as educable mentally handicapped.

The Agency's Voice: Sarah, Steve's Favorite Group Home Worker. I talked with Sarah, while she was watching the Oprah Winfrey Show on television, and while Steve had very loud conversations on the phone. Sarah offered her perceptions on Steve. When I subsequently arranged a formal interview with her, she accepted, but did not show up because of illness. However, she later declined because she was not permitted to participate by her supervisor, and invited me to contact her supervisor first. I relate here some of her perceptions, specifically in regard to Steve's friendships, which evolved during our informal conversation.

As Steve became increasingly angry on the phone while talking with his friend Peter, Sarah explained that Steve is going through a difficult period, one that, according to her, occurs mostly with others at the age of 12 to 15, when they are trying to find out about their friendships. Steve had asked Peter the other day whether he could give a friendly kiss to Peter's girlfriend. Peter had said no which had resulted in a major argument. In such arguments, Steve seemed to learn about his alliances and that after a fight, he sometimes called all his friends to find out whether they are with or against him. According to Sarah, to find out about friendships, Steve initiates fights, after which he tries to consolidate and apologize. A similar pattern is going on with Steve's mother. Recently, he said that he would not be coming home for Christmas this year, expecting that his mother would say that they love him so much. Then they would reconcile, and he would finally go anyway.

Sarah also clarified Steve's relationship with Peter within the culture of the organization, where Peter was a few steps ahead of Steve. Living on his own in an apartment is considered to be more prestigious than living in a group home. Steve anticipates living on his own one day and is looking up to Peter for this. He also looks up to Peter's ability to work in one of the workshops where contract work is being done, which is more prestigious because it pays better. Finally, the fact that Peter has a 19-year-old girlfriend outside the agency makes Steve jealous.

As Steve finished the telephone conversations, he was anxious to tell Sarah everything about them. *"Guess what"*, he said, *"I called three people and I settled matters with two. I called Julie (a person with whom he had a fight at work) and I called my mother and I apologized."* When talking about his conversation with Peter, he became very theatrical

and said that Peter was using the same old trick, cussing and calling him names. Apparently, the fight extended over the phone and apologies were delayed for another time.

The Agency's Voice: Director of Residential Services. The opinions of the director of residential services were expressed in an interview. I compiled her perspective on my interview questions in the following section.

> *"When a school-aged person turns 18, or sometimes shortly before that, the school will contact the agency. Our transition case coordinator will work with school-aged children from 18 until 21 and figure out with them what they would like to do residentially and vocationally, so that they can make the transition from school to adult services. Steve moved into our group home two years ago when it was opened. His family said that he was referred and, in order for him to work, he needed to live in this area because he could not find transportation down here from the place he and his parents lived. He was put on our waiting list until we had an opening for him. In order to live in our group homes, clients have to be involved in some kind of day programming. So, once people are involved with the agency, we do a vocational evaluation, and depending where they fall in the evaluation, we try to meet their needs through the various programs here.*
>
> *Over the past two years, I have seen Steve growing and benefitting from the skill type training that we do, such as being able to write checks, budget his money, doing laundry, cooking. The things that tend to cause Steve the most trouble are relationship-type issues, and those are the issues that are holding him back. Steve tends to be enmeshed with other people, there is no sense of boundary with him. He seems to be developmentally at the level of junior high and there seem to be a lot of junior high-type relationships. One day, one person might be his girlfriend, and the next day, somebody else is. Steve does not seem to get beyond this right now.*
>
> *One of the reasons we had to move him from the first group home (he was at another home) was because of this triangle that was just awful. They*

argued constantly, got into fights, shredding each other's clothes, and doing some really awful things, and it was not a healthy set-up. So, we moved him into another home, with all males, who have a better ability to stand up to Steve, and say, this is not cool. I have seen him make a little progress on it.

As far as employment goes, this is also an area he struggles with. He works in one of the production buildings. Skillwise, he has the skills to be a very good worker. The things that are getting into his way are developmental. He gets into fights with people at work, and he likes to bring his "toy cars" and things to the work site, more than paying attention to his work. When he puts his mind to it, he works very well, he has a good production rate, but right now work does not seem to be his main priority.

In my opinion, the changes that are going on in his family have had an impact on his relationships with other people. The more difficulties there are in the family, and the more unstable that seems to be, the more he seems to really want to be possessive with his friendships, with people.

I think in the future, Steve will be in his own apartment, whether or not it will be in our building where we have the manager there. That would be his next step and I think skill-wise he could do it but emotionally, I don't think he would make it. I also see Steve build a long term relationship with somebody but I do not see that happen right now. He still struggles with the transition to adulthood, he still really wants to go home with his parents. He still can not make that jump from 'I was in school,' to 'now I am an adult, and I need to make money.' He is very capable of understanding some of the reasons why he does the things he does but he struggles with being able to do something about that. He is only 22 and immature, and getting counseling will be very helpful for him."

Sharon

Sharon: Dominant Relationships. Representing the lives of individuals with disabilities in a life history requires the researcher to make an initial decision of format style and selection of information. This is the burden of any biographer. From the data that were

collected from Sharon in a number of encounters with her, her mother and a professional who has worked with her as a vocational counselor, an infinite number of points could be made, ut the challenge is to focus on those that elucidate the phenomenon under study. The research process with Sharon was directed by a goal of attempting to understand the transition from school to adult life for people with mild mental retardation. The research design was directed by the initial insight that the dynamics of this life transition could not be fully understood without conversation with different important players in Sharon's transition. At the same time, I wanted to be sensitive about the perspective of the individual on her own life and favored interaction with the individual, both in time spent and in the depth of the interviewing. Thus, I wished to continue a tradition of life history research which "appreciates that the viewpoints of retarded persons themselves must be included in any comprehensive study of retardation" (Levine & Langness, 1986, p. 191).

The negotiating process for obtaining permission to interview Sharon was mediated by the vocational coordinator who had worked with Sharon in securing a job. Through him, I learned of the sensitive relations among him, Sharon, and her mother. From these initial contacts, I also learned that mediation in the interview process would be appreciated because Sharon felt uncomfortable in conversing alone with a man she did not know. I solved the problem by including in the encounters a female master's student who was interested in qualitative research. Researching the transition from school to adult life as it was experienced by Sharon thus became a team effort, required by the situation.

One dominant theme in Sharon's life that helps to explain aspects of her transition to adult life is the effect of learned incompetence, which means that Sharon has learned that she is a failure and copes with this self-concept in a variety of ways, such as making up stories

and restricting her relationships with people. Her experience is that her incompetence can be hidden until it is uncovered, which unfortunately happens frequently and leads to a great amount of frustration and anxiety. Learned incompetence is played out in the relationships with a very selected number of players in her life. Watching those relationships provided great insight into how Sharon's transition unfolds. Writing about transition to adult life in terms of dyadic relationships between Sharon and important others in her life provided the strongest format, in the sense that writing in this format could further teach how learned incompetence influences the process of becoming an adult.

Relationships and the Transition to Adult Life. In my research methodology, I used multiple qualitative techniques, primarily interviewing and participant observation, but also the administration of the social network diagram. This tool was developed by Antonucci (1986) to map the social network of an individual in three categories: people who are emotionally very close, less close, and not close. We found that Sharon listed most people in the first category and only one person in the last category. People in the first category included her neighbors, girlfriends, mother, father, boss, Linda, and a co-worker. In the last category, she listed another individual from work. Although this instrument gives a picture of the limitations of Sharon's social network, and the absolute lack of persons in the middle category, interviewing and participant observation revealed that the completeness of the instrument could not be trusted. For example, the complete data set revealed that the many hours which Sharon spends at home are shared with her dog and that it might be one of her most important relationships and a strategy for her to overcome repeated experiences of failure.

The first relationship to be addressed--and the most significant in Sharon's life--is the relationship she has with her adopted mother. Sharon's mother is very caring and supportive of Sharon but is also very domineering and perhaps even controlling at the same time. Sharon has described her mother as *"strict, but it's better than being put out on the streets and going to jail."* She definitely sees her mother as the person in charge or the one with the power of final say. When it was suggested to Sharon that she get her driver's license, she responded by saying that Mom said, *"she couldn't drive so she can't drive."* When she was asked whether she would want to live in an apartment someday, she said that her mother had made plans for her to live with them until they died, so she would never live on her own. For nearly every question posed to Sharon about her potential for change, she responded with decisions that had already been made for her by her mother. As a result of not having to make decisions--or not feeling that she is competent enough to do so--she has learned to accept what she is told.

In addition, when Sharon is away from her mother, she does an excellent job of hiding her "disability" or putting on her cloak of competence (Edgerton, 1993). Interviews with both Sharon and her mother at separate times have shown an interesting dimension of their relationship: Mother breaks Sharon's cover every time. Sharon's mother has admitted on a number of occasions that Sharon had someone fooled until she (mother) set them straight about her. Whether it is obvious to Sharon or not, or even obvious to her mother, Sharon's mother tends to be a constant reminder of Sharon's disabilities and lack of competence.

Another significant relationship in Sharon's life is that with her adopted brother Michael. In her discussions of Michael, she describes him as totally opposite of her: he got in trouble a lot; he crashed up cars; he has worked in many different places; he moved out of the house at an early age and then moved far away on his own. When Sharon has put on her

"cloak," she describes Michael as a trouble-maker, crazy, and a problem for their parents. She states that if she acts like him, she'll *"end up in jail too."* However, when her cloak has been removed, she ends up using Michael to highlight her perceptions of her own incompetence. When she talks about his driving record, she mentions that she could never drive. When she talks about Michael moving out of the house, she claims that she could never leave. When she talks about his moving far away, she comes right out and states that she could never be as independent as that: *"Michael is very independent; I am not and never will be."* However, when Sharon's parents discuss the relationship between Michael and Sharon, they claim that Sharon is exaggerating their differences, and they are just like any normal siblings. For

Sharon, it appears as though her brother is yet another reminder of what she thinks she cannot do.

When Sharon talks about her high school life, she discusses her relationship with the other students as one general topic, and it is generally negative. She often compares herself to them and the discussion always results in a list of things they can do that she cannot do: *"They can do difficult math, I can't. They were all in hard science classes, but it was too hard for me."* She talks about how they often made fun of her and that she needed special help to get through school. She had stated more than once that she was much more comfortable after she left school, mainly because she no longer carried with her the stigma that often comes with special education. It is much easier for her to put on her cloak of competence since she graduated and the people around her don't automatically categorize her as "special ed."

Another similar "group" of relationships that can be incorporated here are the relationships she developed when she worked for a sheltered facility. Once again, it was sometimes difficult to maintain her cloak because of the stigma surrounding the facility. She also explained that she didn't socialize well with co-workers because of racial differences. It is difficult to know and understand exactly what did occur with the relationships formed during this part of her life, but she left with very unpleasant memories and the inability to discuss that time period.

In terms of social relationships, the only ones that seem at all significant to Sharon are the friendships she formed with two sisters who are her neighbors. She mentioned going to horse shows with these girls and also mentioned visiting the older of the two at her dorm after she went off to college. On the one hand, Sharon approaches the discussion of her friendship with these girls as representative of how "normal" she is. She never mentions any

stigma, any teasing, etc. However, when Sharon is asked whether she would like to try something that her friends have done or do something similar to what they are doing, she immediately points out that she is different from them and could never be like them. For example, after she visited the one individual at her dorm, she talked very highly of the experience. When she was asked whether she would like to try out college and a similar lifestyle, she said very matter of factly that would be impossible because she could never be that independent and she would never be able to handle the hard classes. Once again, she has distanced herself from someone with whom she has a relationship.

A final significant relationship that should be analyzed is the relationship that Sharon has formed with the family dog, Jackson. In terms of quantity, Sharon spends more time with Jackson than with anyone else in her life. Jackson responds to Sharon more than to anyone else; he does everything she says, he comes when called, he practically looks for permission from her before doing anything. And Sharon perceives herself as having a great deal of responsibility for him -- the word "perceived" is used here because her mother explained that Sharon really has no responsibilities for Jackson (he has a doggy door, the mother feeds him in the morning and washes him) other than to feed him treats and play with him. (This is another example of Sharon's mother shattering her cloak of competence.) But for Sharon, it is the only relationship she has formed in which she has control; she is not questioned and there is no chance that her cloak will be removed. It was obvious that when she becomes nervous or uncomfortable, she turns to Jackson to regain her confidence; it may be the only relationship in which she is totally comfortable.

There are several other significant relationships in Sharon's life that affect her history, such as her boss at work, her co-workers, her counselor/case manager, and boyfriends. With

more information about each one, we would be able to form an even clearer picture of Sharon's life.

Brian

Brian: Getting Stuck in the Transition from School to Adult Life? My first impression of Brian was of a young person in his early twenties, glasses, jeans, saying hi, and visibly a happy person. Even though he said later that "cerebral palsy is messing me up," there is something indestructible about Brian. The effort that Brian puts into communication and in walking, and his patience with people stands out. Communication with Brian for someone who has very little experience with him is a challenge. His speech is difficult to understand, but he patiently repeats and tries again, and if that does not work he writes the word down. Communication is tedious, a hit and miss game, as in the following interview excerpt:

Interviewer:	*Your two brothers, what are they doing?*
Brian:	*Teacher.*
Interviewer:	*One is a teacher?*
Brian:	*No. School.*
Interviewer:	*He works in a school?*
Brian:	*No.*
Interviewer:	*He goes to school?*
Brian:	*Yeah. Two.*
Interviewer:	*The two of them go to school?*
Brian:	*Yeah.*

As I tried to communicate with Brian, and experienced frustration, I became aware of my own limitations in understanding him. I tried to enhance communication by asking him to type in words on the computer. It was of little help. I understood that such listener incapacity

would limit Brian's opportunities to get to know other people and confine him to people that take the time to go through a learning process that enables them to understand Brian. Family members are able to understand Brian very well, and so are some of his classmates in high school and some agency personnel.

I was also able to speak with Brian's mother by phone but was unable to meet with her. Brian's vocational coordinator had described her as a friendly person but suggested that I should try to speak with her by telephone since she worked full time. She agreed to speak with me on the phone and agreed that the conversation could be taped. It is from this conversation that I developed her perspective.

It is the limitations of communication and the limitations of ethnographic life history work that forced me into doing more participant observation, and becoming more aware of the spaces in Brian's life and their relative importance as markers of life transitions. These insights have driven the format of my description and insights of Brian's life transition in terms of different spaces. I distinguish them as primary spaces, old and new places.

Primary Spaces: Brian's Town, Home, and Room. Brian lives in a rural town of 400 in Illinois, which is surrounded by agricultural land. It is structured on a grid, with streets simply called first, second, third, etc., and cross streets named after various states, with the exception of the streets on the very east and the very west, which are called Eastern Street and Western Street. As in many American towns, there is Main Street with an antique shop and a gas station. Four huge silos overlook the town. When I told Brian that I had difficulty finding his house, he said *"no numbers."* Perhaps the houses did not need numbers, as everyone knows everyone else and residents pick up mail at the post office. The county is rural as well, with an overall population of about 14,000.

Brian moved with his mother and two brothers from a larger town in Illinois to the small town in 1985; he had lived in two larger Illinois towns before his family moved. Brian currently lives with his mother, stepfather, and two brothers. His mother decided to move to the small town because her own mother and brothers live there. Brian's mother has been married three times and has one son from each marriage. Brian's father lives in Hawaii. At the time of moving into the town, Brian started in his new high school. His mother started new work in a company that deals with corn seeds. She remarried in 1987. His stepfather works on auto bodies in a different town. Brian described the early morning in a graphic way: his mother leaving with her car in one direction, his stepfather with his car in the opposite direction; and his brothers to school in the same town, at the end of the street. Brian remains at home, in the company of several pets, the noise of the dryer in the background, and his own room, equipped with stereo, TV, and VCR. If the weather permits, Brian rides his adult tricycle. He is proud of his equipment, and of the fact that he has two bikes.

I was privileged to enter Brian's kingdom, his own room, adjacent to the dining room. He showed me the water bed he bought with money that family members gave him for his graduation party. As in other parts of the house, all sorts of things accumulated. A big poster of Billy Ray Cirus, a pop-star who is popular with many young people, was on the wall. When I asked Brian about him, he showed me an even bigger poster, too large to display in his room and a compact disk of Cirus. He was very proud of his remote control stereo, new TV, VCR equipment, and of his collection of compact disks and videos. I also noted a white paper attached with transparent tape on the wall just above his desk on which Brian had jotted with crayon, "I love Heather." In his room, letters from his father are visible as well as

a check for $50.00. Brian talks with his father on the phone about once a month, according to his mother.

Brian spends much of his week at home. Their house is situated on Western Street. The entrance porch needs repair. A wooden board prevents people from stepping through and falling. The house inside reflects the life of people who spend most of their time away from the house, with little time to clean up. Pictures, screwdrivers, clothes, food, dishes, and the like accumulate in different parts of the house, reflecting a value system that puts order as a low priority. Many plants, two birds in a cage, a white cat called Snowball, and a black and white puppy which just made its entry into the household make it a lively place.

Brian likes his younger brother quite a lot. Taller than Brian, he is on the high school basketball team. Brian goes to see the games during the weekend. Although Brian could independently get on the bus that comes to pick him up, his mother prefers that one of his brothers assists him. On his stepfather, Brian is very silent; he would say only that things were fine.

Old Places: School. Brian has good memories of school. He remembers some of his peers helping him to walk and carrying his books to class. He says he saw other children getting into bad fights, but he was not part of this. People were nice to him. His favorite subject was history. He especially has good memories of one teacher's aid, who made him laugh by talking funny, and who helped him with writing things down, and getting an A+. He also recalls playing Yahtzee with one of the teachers.

At school, Brian's mother observed that Brian had *"a few close male friends, they went through classes together, but there was no extra activities after school or anything."* Brian benefitted from school, according to his mother: *"He is able to sit and look at a book,*

how to hook up a stereo, he'll read how to do it and then do it, that kind of stuff." Brian's mother was invited to attend meetings and usually attended. She and the school staff discussed *"possible goals to be reached there at school and what possibly he would be going on to do after school. But they weren't really sure what he was going to do after that. He started to go through the Department of Rehabilitation his last year of school. He went afternoons and worked at the County Resource."* It appeared that Brian's mother did assign most of the responsibility to Brian's school, or at least expected to find some direction. However, she found little interest and abandoned the process.

From her visit to the County Resource workplace, Brian's mother remembers that *"Brian was at a table with about six people but nobody talked. And I told Brian later, 'Boy Brian, that job would be so boring. I mean you guys could at least carry on a conversation while you're sitting there working.'"* This work experience did not lead to a job. Instead, Brian finished high school and returned home. He was suddenly without any professional support. The people at the Department of Rehabilitation Services were no longer responsible for Brian because he lived in a county in which he was the responsibility of a different office. Brian's mother did not realize that the next office had not picked up Brian's case until she started to inquire. She minimizes the impact of the time that was lost because of this: *"It was not too long of a time, just like a summer vacation when you're out of school."*

Graduation. When Brian graduated from high school, he had a graduation party, about which Brian was not very excited. He says, *"We eat cake."* It was mostly a family event, and he appreciated that *"all my cousins come. My Dad come."* He did not get any presents but he received money with which he bought a waterbed, a continuing symbol of his graduation. Perhaps the reason that Brian was not too excited about the party, was that it was

not followed by any plan for the future other than staying at home, riding his tricycle, and becoming very bored.

Brian's mother reflected upon Brian's graduation as *"basically family. We had an open-house at a little hall in town. His Dad and I are divorced but his Dad had made it for the graduation and his grandparents on his Dad's side and some of his aunts and uncles and aunt and uncles and cousins from my side of the family."*

New Places: The Center. Two days a week, Brian is picked by a bus that takes him to a county mental health agency in a larger town nearby. The place is brand new: it smells new as you enter. Some of the driveways outside are not yet finished. As you enter the building, you can go left to "developmental services," or right to "counseling services," a structural division that divides people into those with mental deficits who are not considered ill and those who are. I noted the homeyness of the country-style furniture and wallpaper near the ceiling, but also the clean whiteness of the floors and walls and the large spaces which reminded me of an institution. Brian has been involved in several activities at the developmental services side of the building, such as working on a computer learning about data-entry, cooking, and some contract work for which Brian gets an allowance. The purpose of these activities is to increase his opportunities for independent living and working. His vocational coordinator has been working with him to find a job, but so far he has identified nothing suitable.

As Brian became connected with the agency, his outlook on life changed. Both he and his mother conceptualize the connection as "work," although the agency does not see it that way. Getting involved in the agency's training and various activities gave him a sense of purpose, which may explain why Brian looks like a happy person. At the agency, during

cooking lessons, he became acquainted with a woman whom he considers his girlfriend. The relationship is not firm and they have made no plans, but he shared his feelings with his mother. Possible outcomes of the relationship are highly contested by his mother and ignored by his vocational coordinator; in fact agency personnel may feel uneasy discussing these topics. Out of these experiences and the conversations with counselors, he developed a desire to move out of the house and imagined himself living in an apartment in town near the agency. However, because the notion of work is itself contested among the various perspectives, and because moving and living independently tend to be linked, plans to move out of the house have not materialized.

Since his current involvement with the agency, Brian has become *"a lot happier because he's with people that are more like he is, all the time, to make friends and everything. I think he's a little more outgoing even. Where he's at now, he has a lady that has a group of people and she takes them to dances or picnics and cookouts, so there's more of a social life, you know."* The agency filled the need of *"keeping him going"* after a period out of school, a period characterized by emptiness and boredom. *"When he got into this program that he's into, I was really glad because, I mean, that really gives him something to do."* She is also happy about his improved communication with people, *"Where he's at now, I mean, they communicate a lot better, and that's one of his goals, to sit down and make conversations with people just to keep him going."* In a similar vein, she comments on the reasons why Brian cut a summer visit short to his Dad, saying that *"he got homesick and needed to get back to his work and everything. He's got to keep busy."*

Since Brian has been involved at the county mental health agency for the last three years, he has been involved in different activities, and agency personnel have made

significant efforts to develop their capacity to help Brian. Two subtransitions have been of major importance for the agency: his transition to work, and the attainment of skills for independent living. These activities have led to new social contacts within the agency.

As part of Brian's transition to work, he has been involved for the past three years in vocational classes and in a job club where employment-seeking skills and appropriate behavior at work are addressed. Much time was spent in teaching Brian about such topics as appropriate conversation during lunch breaks, what do you say to a supervisor when you don't like the job, and working on a resume.

Brian's involvement in the agency is positively evaluated, as shown by this file excerpt:

> *Brian is a very pleasant young man who is personable and enjoys participating in a variety of activities. He is very eager to try the job. He independently sets up his own work area and goes right to work on task. Brian respects authority and other people and their belongings. He participates in every group activity offered and enjoys interacting with staff and peers.*

In trying to assess Brian's capabilities, it was noted that he *"responded in single words, phrases, or 'telegraphic sentences' in which words were omitted. He did not initiate conversation during the assessment session, but responded briefly and appropriately to direct questions and occasionally responded on topic information in addition to his initial response."* Staff reported that Brian seemed *"overly agreeable and seldom voiced an opinion."*

The agency became fully aware of the limitations that would be imposed on Brian's work opportunities because of the difficulty of communication. The agency decided to

purchase computer equipment with enhanced reading and voice synthesizing capability which would enable Brian to enter data. However, the equipment arrived only after Brian had already spent more than three years at the agency, and at the time I visited with Brian, the staff were struggling to learn how to use the equipment, and he worked on it only once a week. Brian's limitations in spelling words correctly seemed to be another hurdle in training him. If Brian were offered a data-entry job, the agency equipment would not go with him; his employer and a rehabilitation agency would have to purchase similar equipment.

Brian's vocational coordinator is Mark. His responsibility at the agency is to work with Brian on employment-related issues. Mark found that Brian came to the agency with very little vocational training and very little vocational planning. He commented that *"the job search has been something that's been very difficult for him to decide what he really wants to do job-wise because he really didn't get any work experience in high school. His biggest memory of vocational involvement in school was back when he worked in the library in grade school. It's really neat that they gave him some kind of vocational aspiration way back then, but it's too bad that didn't continue on through high school, or it apparently did not."*

Mark's perspective of Brian's transition to adult life is influenced by his role at the agency in vocational services and the overall services that are provided. The services which are part of developmental services offered are vocational, developmental training, case coordination, residential, and independent living skills. Although the primary focus of the vocational services program is community job placement, the agency also does some contractual work, although it is not a full-fledged sheltered workshop. Under Mark's initiative, the agency started a recycling program, mainly can crushing. A newspaper article, neatly displayed in Mark's office, describes this initiative. Brian worked on this project as

well as in some other contract work, which gave him extra money. Mark described Brian as involved at the agency in job hunting, and "doing vocational training type of things like data entry, computer work."

Brian came to the Mental Health Center six months after graduation. Brian changed residences and should have been transferred to the rehabilitation office that serves his county. Mark commented that:

> *It's supposed to be a smooth transition. The counselor of [the rehabilitation office which serves his high school] was supposed to make sure that the [counselor which serves Brian's home county] got invited to the IEP staffing for the last year at least, maybe two, before graduation, so there is that smooth transition. Plus, if there needs to be a referral for our agency, that would hopefully occur the last couple of years before graduation if it hasn't already occurred. Well, Brian's case was not transferred from the [office which serves the county of Brian's high school] to [the office which serves Brian's home county] until he had graduated. He didn't have a job. Very little vocational planning had occurred. He and his rehabilitation counselor came to us about six months after graduation, and that's when he started getting involved in some different job training options.*

As Brian lives at home, another person from the agency who works in a program called Community and Family Support Unit visits Brian once a week at home to give support in independent living skills, such as bill paying, cooking, laundry skills, shopping, and budgeting. Mark understands that Brian would *"eventually like to get an apartment, either with a roommate or on his own."* Mark sees Brian start to live independently within a year or two: *"It's not that he doesn't enjoy living at home. I think that, my sense of it is, he's just a guy that realizes he's old enough to be out on his own. That's something I should do. That's*

what most people my age do." Mark sees Brian's mother to be supportive in his desire to be more independent that way, *"to have a 'normal' kind of a set up for someone his age."*

Mark noted that Brian has a buddy he'd like to have as a roommate. However, he is not sure whether an arrangement with a roommate would eventually work out: *"My hunch is that whether the buddy will go along with Brian's time line or not, Brian will probably forge ahead with it. My sense is that the buddy is less anxious to get out on his own. I can see it working well for Brian with the buddy or without. He's the kind of guy who would do well on his own regardless if he had a roommate or not."*

Mark finds it unfortunate that Brian has to depend on his mother and the Center for his transportation, partly because there is not a lot of public transportation. In rural areas, having a car and knowing how to drive is a big part of being independent. Brian's trips are pre-arranged. The agency does not have plans to increase Brian's mobility independence.

Mark's perception of Brian's social life is again colored by the services his agency provides. Brian met his buddy through the different work programs and the Special Olympics program for the county. Mark's agency is a sponsor for the Special Olympics program. Brian became a team manager for basketball and volleyball. These are sports in which he has difficulty participating. However, Brian does participate in bowling. Mark finds the Special Olympics *"a neat social thing. They get together all the time. Go out of town and this and that. Brian just turned twenty-one and they got together. They got together for festivals and things like that and have a good time together."* Mark does not comment on what Brian's social life was like when he was in school.

Mark became very unsure about Brian's girlfriend, Heather. An area outside his professional arena, he felt uncomfortable commenting about it. He said: *"I have no idea. The*

sky is the limit, I suppose. I've never asked too many questions. I've just caught bits and pieces."

To summarize, Mark's investment in Brian's transition to adult life is highly focused on the transition from school to work. Mark recognized delays in this transition which he partly attributes to insufficient vocational training during high school, lack of vocational planning, and lack of coordination between rehabilitation agencies. He also recognizes more delays in having the vocational training within his own agency going, due to the time needed in getting adapted computer equipment and becoming acquainted with it. In a report he writes: *"Brian and his team discovered that the process of investigating, selecting, purchasing, and training with adaptive equipment, can be a lengthy and painstaking process, which has delayed Brian's movement toward job placement."*

Although Mark sees job placement prior to living independently as the appropriate sequence in transitioning to adult life, he goes along with Brian's wishes to move out on his own and live independently from his parents. Although he conceives living with a roommate to be ideal, he has doubts whether this will work out and would be supportive of Brian living independently in an apartment. With the prospect of employment still being unsure, the agency would continue to provide transportation for his activities.

Ultimate Place. For the near future not much change was anticipated, except for *"him living here at home and going to work like he does every day. I don't think we have any plans to change him right off [into another job]. He seems interested and I don't know whether it's just a matter of time or til he gets it."* In the more distant future, *"I possibly see him moving into one of those apartments or homes where you pretty much take care of yourself but there*

are people there too, [However], there's no reason that he needs to, but it's just what he might want to do."

Brian's mother does not project an idealized life-course. *"He has the hopes of wanting to get married and live on his own and everything. But I don't know how realistic that'll be."* She understands that Brian has those hopes as *"he's just like any normal male wanting to get married and have a life together."* However, she does not think that Brian will ever marry his current girlfriend.

Brian is caught between his family and the institutional support. Despite the obvious impact of his disability on his walking, talking, and learning, life has not been made hard on him either in school or in the family. He did not get into fights with other students but rather was isolated, with very few male friends. Their friendship did not go beyond the school. His family has been a haven, a place of comfort. At the time of graduation, Brian had not made any plans for himself, and neither had his parents, his teachers, or his rehabilitation counselors. Brian further got lost in the rehabilitation bureaucracy which confined him to his home and riding his tricycle until his mother realized it and initiated the process again. His reconnecting to an institutional setting may be interpreted as bringing meaning to his life through daily routines.

In his family, only his mother seems to be particularly concerned. Initiative in his family is not found very necessary. There are several underlying values that seem to determine family initiative: relying on the institution to come up with solutions, relying on the friendliness and the tolerance of the small town, his mother's own tolerance and protection, and the extension of this on her side of the family. Creating the comfort of the

small town and the family environment contributes to Brian's dependence and his lack of decisiveness.

The agency perspective is characterized by professional fracturing of responsibility over different aspects that relate to perceived problems as they define them. Without the lack of problem definition coming from the family, Brian becomes part of some of the activities of the agency that could be of benefit to him.

Did Brian get stuck in his transition to adult life? Yes, but the irony may be that neither he nor his mother may have been aware of it and avoided giving it much thought. According to the vocational coordinator, Brian's mother *"may not have been aware of her rights."* From her perspective, she might have thought that the comfort of the house, the daily routine, and the small town friendliness was the best she could offer Brian. Brian missed the opportunity of preparing himself for employment and a sequence of events that would connect him more closely to the lives of many other Americans. Employment still is the imagined first goal which gets the ball of transition rolling. However, for Brian, his involvement in the agency and its routine may already have replaced employment in the community, which may now have become the responsibility only of the agency and in his own mind secondary to trying to move out of the house of his parents.

Contested meanings among the different stakeholders of possible outcomes in Brian's transition to adult life, such as work, living independently, sexuality, and mobility, lead to different interpretations of the flow of events in Brian's transition and its judgment. If the professional's perspective is characterized by an idealized conceptualization (e.g., Ferguson et al., 1993) of the transition that incorporates both the occurrence of events and their effective and smooth sequence, there is no doubt that Brian's transition was empty and took too long,

which brings him into a situation of ongoing transition, characterized by indecision. However, the calmness of Brian's mother in evaluating the situation and Brian's own positive attitude suggest that this is only a partial picture. Although her former experience with agencies does not lead her to expect concrete nor immediate outcomes, Brian's mother waits for things to work out from the connections with the agency. Meanwhile, she appreciates the meanings that she and Brian derive from his involvement there. The more important thing for her is to see that "the agency keeps him going" rather than concrete outcomes. In my interpretation, this evolves out of a reading of an important value in American culture. Her value system is much more unsure about whether Brian needs a job, needs to live on his own, or can have a married life. For answers to those questions, she looks to Brian's agency, and ultimately to Brian himself.

Brian's happiness similarly suggests that "keeping him going" counts most, at least for now. The alternative is not so much the ideal script, which consists of "a job and an apartment in the community" but being confined to the home all the time. The professional counseling brings Brian into contact with ideas that are part of the ideal script, for example, working in the community and living with a roommate. These ideas socialize him more in the direction of an individualized and independent life.

Space and Life Transitions. When thinking of life transitions and the conquering of space, the image of the Marlboro man[1] is a good start. He is the rough cowboy who, in a moment of stopping time, oversees vast spaces, probably takes the time to evaluate where he is in life. It is a popular image, much a part of American culture: personal expansion, making it on your own, and the building of the country all summarized in the phrase, "go West."

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[1] I wish to acknowledge Marcus Griffin for suggesting this analysis

Brian explored his going West in visits to his father in Hawaii and decided that he could not do it. His mother found that after some time, he needed to get back into his daily routine and be home. Brian holds on to the idea of moving out of his mother's house, but his mother does not see it happening within the next five years. For now, Brian seems to be trapped. His trips to the adult agency have not resulted in making it on his own in any sort of way. It has given him the security of a place to go; here he met his first girlfriend, and maybe some of his first friends, and it is here that he picked up the idea of being on his own. But all this has stalled into dreams, without any concrete outcome. From Brian's life history, I learned that expanding one's space is an important dimension that goes along with life transitioning.

Through the exploration of four life histories, I clarified the process of the life transition to adult life. Tina's life history (chapter III)helped in establishing a basic framework. I made this framework more complex by stressing the importance of different perspectives and the importance of mediation in Steve's life history. I also clarified the importance of social and physical markers in the life histories of Sharon and Brian, respectively. This complex understanding will now be the background for introducing the other persons in the study. Apart from introducing the persons and briefly clarifying their transition, I will also present some of the ethnographic work.

Lori

Lori, 25, was born with hydrocephaly and a bilateral cleft palate. With special education and vocational training, Lori has graduated from high school and is now working as a volunteer in her community. Her life, however, is not one of independence nor is it one that is appropriate for an adult of her chronological age.

Lori's grades in high school were not good enough to get her into college. Along with some other girls from her area, she enrolled in a child development training program. After the first year, however, Lori and some of the other girls pulled out of the program because the teacher stereotyped girls from Lori's town and made derogatory comments about them. Lori's parents did not look into the situation or tell Lori that she had to go back, and they did not determine if anything could be done to rectify the situation.

Lori cannot handle any type of pressure or stress, according to several outside observers, which is why she prefers volunteer positions where there are no demands or responsibilities placed on her. Lori is very scared of employment. She is capable of holding down many different kinds of jobs but does not have confidence in herself. Her caseworker, Sarah, believes that counseling would help Lori to overcome her fear of failure and teach her how to deal with high pressure situations, but her mother declines the service. As long as Lori does not need to work for financial reasons, her problem will not be resolved.

Lori has had several jobs during and after high school. Her first job, during her senior year, was a part of a work-study program that was offered to her through the school. She did not take any initiative in finding these jobs for herself. She worked for part of the day and then had academics for the other part. Lori said that she chose to work in a kindergarten classroom because she knew the teacher from when she was in kindergarten and felt comfortable there. In addition to this job, Lori also worked at the library in town. This was the library that Lori had grown up using, and all of the librarians knew her. When she was offered this job, she took it because all of the librarians who worked there were her *"dear friends."* Lori thought that both of these positions were for pay, but she never received any money for her services. When asked if she followed up on it, Lori replied that she just left it

alone and decided that she was not going to bother with it. She said her parents did not do anything about the situation, and they just left it alone as well.

After spending a year in the child development training program, Lori began volunteering at a hospital. She said that she loved that job because she liked making people feel better by talking to them. The job, however, only lasted a year because her carpool was discontinued. Lori had no other mode of transportation and no knowledge of how to take public transportation. She is capable of following a bus schedule and getting from place to place. However, if the bus is late for some reason or if she has to go to a different place, even if it is a block away, she will panic. She seems to have no concept of waiting for another bus, or calling to see what the problem is, or even possibly getting on a different bus.

When Lori is confronted with these situations, she calls home. Lori's brother, Andy, commented that his parents made many trips to other towns to pick her up and take her to where she needed to go. This became such a problem for her parents that Lori had to quit her job and find one that she could get to on her own.

Her next job was working in the fitting rooms at a T.J. Maxx clothing shop. A friend had told her about this position, and Lori thought it was a good idea. She thought her interview went well and was excited when she was told she had the job. She got to work by a carpool. This job lasted until she was fired. Lori said that she was fired because one woman complained about not being able to take more than the maximum number of items into a fitting room. When Lori stopped her, the woman reported to the management that she was rude. It appeared that Lori was fired by the store because she was following store policy. No one in her family clarified the situation or the whole story. So again, Lori was out of a job.

Lori was not distressed by this fact because she knew that something better would come along. She had no concept of what kind of problems she would run into if she had to support herself financially. Eventually something else did come along, another volunteer

position at the local museum. The woman who managed the museum was a friend of her mother's who had suggested that Lori work there as it was an "easy" job with no pressure or deadlines. The museum is also within walking distance from her house, which eliminated the transportation problem.

Lori plans eventually to find a paid position in some facility. She would like a job in data entry or child care because those are the two fields in which she feels she is good. She refuses to get another job in the clothing business because she feel she is not good at it. Her parents have told her that it is fine with them if she doesn't want a job in that kind of a business. She also stated that she would look for any kind of job that did not have deadlines, supervisors looking over her shoulder, or any added pressures.

Lori has lived in her house with her family for all of her 25 years. However, Lori does plan to move out on her own. When asked why she wanted to move out, Lori stated that she did not have enough room for her things, that her mother always brought stuff home from their store, and her closet wasn't big enough to hold everything. She made no mention of wanting independence.

She feels that if she were to move out, she could take care of herself. She said that she knows how to cook her own meals, make her bed, take care of her hair and manage her clothing. In actuality, her mother tells her when to take a bath, how to do her hair, what she should eat, and what she should wear. Every time we met, Lori was wearing an outfit that was similar to her mother's. Lori made no other comments about what she needed to be able to do to live on her own, such as pay bills, grocery shop, do laundry, and cook. Her brother stated that her mother does all of these things for her, and Lori has no idea how to do any of them independently. In particular, she has no understanding of financial matters and what is

needed to survive financially as an independent person in the community. Lori is not ready to make any steps towards looking for a place to live or a roommate. She indicated that if someone came to her looking for a roommate she would look into it, but only if they came looking for her would she consider moving out.

Lori talks a lot about spending time with friends, looking into other friend's life situations and how they have handled similar problems. However, when she was asked to name specific friends, particularly close friends, Lori was only able to name one person. Throughout the interviews, she would often refer to older people as her dear friends. Besides her friend down the street, Lori never mentioned any friends around her age or having plans with anyone besides this one friend. She said that she spent a lot of time with her family, particularly her mother and grandmother. Her brother Andy says that she spends most of her free time in her room with the door shut either listening to music or playing on her computer.

While Lori talks a lot about her friends, she really does not have what fits the age-appropriate definition of friend. All of her friends are really her mother's friends. Lori has never been able to mention a friend of her own whom she calls and makes plans. Mostly, the people Lori calls friends are actually acquaintances, her classmates in high school who would pass her in the hall and say hello but nothing more would ever come from it. Lori would like more social opportunities, but she is not searching for them.

According to Lori's case worker, Lori and her mother both want independence for Lori but they are not actively pursuing it. They are, more or less, waiting for independence to come to Lori. Therefore, Lori is receiving mixed messages from home. She should be independent, but no one is giving her the guidance she needs to achieve it. For example, when the caseworker would ask Lori to go home and think about the things they had

discussed, Lori would come back and tell her what her mom thought about the situation rather than her own ideas (e.g., *"we think I should do this", it was always "we" instead of "I"*). Andy states that he really believes that Lori would be in trouble without their mom.

Andy observed that Lori is very aware of her disability and doesn't like to be around people because she is afraid of what they might say. She is extremely jealous of Andy's girlfriends and often has huge crying tantrums after they leave. She wants to know why she can not be more like them.

The biggest problem, Andy has found, is that their parents, especially their mother, does not want to let go of Lori. She is extremely worried about Lori and is reluctant to let her become independent. The lack of encouragement in becoming independent observed is not a reflection of the emotional support Lori receives from her family. In her interviews, Lori constantly stated how her parents, especially her mother, are always there for her emotionally. They reassure her at stressful times in her life and tell her that all they ever want from her is her best.

In conclusion, at the age of twenty-five, Lori is just beginning to make the transition into adult life. Outside observers believe that in time and with assistance of rehabilitation centers, Lori will be able to live on her own in some capacity. In this particular situation, what is needed from Lori's family, or any source of support, in order for her transition process into adult life to be successful, is (a) the initial inquiry, (b) the initial push, and (c) the continual encouragement to follow through. This lack of encouragement in Lori's situation is apparent in interviews with Lori, her case worker, and her brother concerning her living situation, work experience and training, social life, and her relationship with her mother.

Pre-Transition

Dennis

Dennis, 18, has received special education for learning disabilities, mostly in reading, for much of his school career. Once, he was also placed in a class for students with mild mental retardation. Dennis is very hard working. In his last year of high school, he was placed in a work-study program that alloweds him to leave school around noon. He works several jobs and gets home around midnight every day; Dennis also spends weekends working. He explained that after he saw his father go bankrupt and his family move from their farm into a trailer, it occurred to him that he did not want a life similar to that of his father and that money is important.

Dennis has a long work history. He started to work at the age of 12 for his cousin's husband, a farmer, during the summers. At 16, he worked for a mud racer for two years, where he learned to build motors. Now he plans to work for the farmer again after graduation. In addition to a year's salary, he will be given a house and a new truck. He can also work other jobs during some of his free time. Dennis has worked at jobs like dry wall plastering, wallpaper hanging, painting, hauling grain and gravel, working with concrete, and yard work. Dennis learns by observing and imitating jobs. He relies on his own transportation and has owned several trucks.

Dennis's relationship with his father was disappointing. At a young age, he learned that his father did not keep his promises. The youngest of five children, and the only one still living at home, he has a good relationship with his mother although he does not see her often because of her work schedule. Dennis finds that he has done well compared to his brothers and sisters. Dennis has had few good friends. He said that the situation changed when he

started in special education and some friends turned their backs on him. However, he still has some good friends, students both in and outside of special education. Lately, though, he has not spent much time with them because he has a girlfriend. Upon graduation, Dennis plans to move immediately into his own house and get married. Even though he is still in school, he has been arranging for furniture and other needs for the house. Dennis's mother worries because his girlfriend is pregnant and the situation may become overwhelming. His teacher, who has known Dennis and his family for a long time, believes that Dennis has enough skills to do well, but she also foresees some problems. In all probability, Dennis' transition will be complete. His friend, and employer, will be the most important mediator, and his transition will include both social and physical markers.

Joyce

Joyce, 18, is living at home with her parents in a small town. Her high school is just a few blocks away. Joyce has lived in the town all of her life and is the eldest of three children. Both she and her younger brother have had problems in school and received special education. Joyce's disability is expressed in academic problems. Joyce's mother connects the disability with problems at birth. Her mother explains that Joyce is not a typical special education student: she has problems with some subjects, such as math, but is very good in others, such as history, in which she developed an exceptional interest. Her parents keep a very close watch over her work although, on her own, Joyce works very hard and is meticulous. Joyce's parents are both registered nurses and work in a city 35 miles away. The family belongs to the Church of Jesus Christ of Latter Day Saints (Mormon), and the parents have very strong moral values that they teach their three children. These values influenced Joyce and she does not easily tolerate other values. Most of her friends are from her church.

She does not have really close friends in school because she tries to impose her values on others, and she sometimes finds it hard to fit in.

Joyce has worked as a Easter bunny in a large shopping mall during the Easter season. She likes to be around children and has made plans to go into a child care program after high school. Her father helped her find a school and to register in a program that is run by their church. According to her mother, the initiative taken by the public school for Joyce's transition came too late. Joyce looks forward to leaving her town and living in another place. She thinks that living on her own will work out well. Joyce has dated a few boys, but according to her mother, the relationships were never anything serious. Joyce would very much like to find the right person, be married, and have her own family. I conclude that although Joyce was still in school when I worked with her, everything seems in place for Joyce's successful transition. Her entry into a school was mainly mediated by her father, and indirectly by her church, and interestingly, only to a very limited extent by the school. Her transition will be characterized by physical and social markers.

Post-Transition

Diane

Diane, 29, was born with Down Syndrome. She currently lives in an apartment that she shares with a roommate who has cerebral palsy. She works in a day care center in a metropolitan area. Diane comes from a professional and Jewish family background. Her father is an attorney and her four siblings, who are older, are highly skilled as well. Diane's mother was a journalist but adjusted her career to become a special educator resulting from her experience with Diane. Diane's brother is a Ph.D. candidate in special education. Diane's parents initially relied on the services provided by the Jewish community but gradually

accessed other services. Diane was educated in a surrogate family while she was young and resided in a Jewish group home for some time after graduating from high school. The professional environment of her family has strongly influenced Diane. This is evident from her use of special education language in interviews. Her involvements in professional activities such as the yearly congress for persons with Down Syndrome and the day-to-day contacts with her family members reinforce this use of language. Diane has a "Circle of Friends" (Perske & Perske, 1988) who help her plan her future, including her employer at the day care center. Although one could conclude that Diane's transition was completed in terms of social realignment and physical markers, it seems that it lacks stability. The reason is social and must be found in Diane's family background and the difficulty of finding social relationships that match Diane's needs and preferences.

Karen

Karen's mother explained that letting Karen move into a group home was the greatest gift that she ever gave to Karen. Six years ago a new group home was built just a few miles from Karen's family's home, and Karen was among the first residents accepted into the new group home. She has not lived anywhere but her parents' home and the group home. Karen is in her mid-twenties and has cerebral palsy due to complications from her birth. Besides her parents and two brothers, Karen has many relatives in her hometown. Karen's mother thinks that the large number of relatives and the *"closeness"* of the family has been good for Karen. As her mother explained, being even a few miles away from her family gives Karen much greater opportunities for learning to get around in the city and for making friends. The price of the gift for Karen's mother is clearly her fear for Karen's safety.

In order to stay in the group home, Karen must work, and currently she works in a sheltered workshop. She has also worked in supported employment and at a job in the community. It is Karen's work experiences, and in the contrast between Karen's living situation and her work experiences, that the story of her transition lies. Karen's move to the group home was the most significant aspect of her transition for Karen's mother and the move necessarily brought changes to their relationship. While her living arrangements have remained stable, Karen has experimented with several work settings. Her movement between jobs is due in part to the different goals held by Karen, her mother, and the group home staff. Struggles over jobs are a likely preview of negotiations that will appear in other contexts in Karen's life in the future.

Working with Karen. Several appointments were made before interviewers were finally able to meet with Karen. The first appointments were set, but Karen canceled or did not show up because some other social events came up or she forgot about the appointments. When the interviews did begin, Karen never said very much although she always seemed excited when the interviewers arrived. Karen said she is happy in the group home and does not want to move. She did seem comfortable there. She was most animated when talking about her pet bird. During interviews Karen did not remember much about her school days except that she liked math a lot. She was not talkative on any subject, but only seemed uncomfortable and really did not want to talk on the subject of her boyfriend. She mentioned missing an interview because she was having dinner with her boyfriend, but when she was asked about him, she seemed embarrassed and did not want to respond; the topic was not

pursued. After the interviews, Karen and the interviewers would go for a soda or milkshake at a restaurant. Karen seemed to enjoy this, but she talked even less while in the restaurant.

Background. Karen attended special education in public schools. When Karen was twelve years old, her mother read *The Brain Child*. The book tells the story of how this young girl with mental retardation went through a therapy called "patterning" that, as Karen's mom described it, *"teaches the other parts of the brain to make up for the one part that is damaged."* The picture on the back cover of the book showed a girl who "could have been Karen's twin sister."

Karen's mom was unhappy with the school system because the teachers never had anything positive to say about Karen; they only discussed what she could not do. Impressed with the book and ready to take Karen out of school, Karen's mom called to find out about the institute in Philadelphia where patterning therapy is offered. Not only was it far away and very expensive, but there was also a long waiting list. Then Karen's mom found out that there is a doctor in a city nearby who practices the same therapy. Karen's mom went to this doctor to be trained in the therapy. Then, she and Karen's father, who is an electrician, built the necessary equipment and converted their basement into a training area. Karen's mom removed Karen from school for all but a few hours a day and proceeded to practice the therapy for 7 and a half hours a day, seven days a week. Although they worked with this therapy for more than four years, Karen's mother said that this therapy did not work miracles for Karen, but she believes it is very effective for some individuals. The intense therapy went on for many years.

Karen's mother did not accept the negative evaluations that Karen received at school. She did not accept teaching methods that required the student to perform a task repeatedly

before moving on to the next lesson. If a student refused to perform a task so many times, Karen's mom believed that the refusal reflected boredom more often than inability. She also did not accept the way some school administrators wanted to dismiss her comments at school meetings. The fact that Karen's mother took Karen out of school and pursued the arduous task of patterning therapy reflects her refusal to accept wholeheartedly established guidelines for students with disabilities. Karen's transition reflects her mother's refusal.

Karen's Transition. The goal of the group home staff has been to help Karen become more independent. The group home manager cited Karen's many achievements over the past several years as evidence of her progress and potential for greater independence. The manager especially remembered the day that Karen requested that the staff get money from her account so that she could buy a new pair of shoes. Another resident of the group home who knows the city bus system well went with Karen, and they bought the shoes on their own. Buying shoes on her own marked Karen's increasing independence. Karen had no cooking skills when she entered the group home. After only a few months in the group home, however, she prepared a large spaghetti dinner and proudly invited her mother to attend. Although Karen still needs to work on keeping her room clean and some other skills, the group home manager is convinced that Karen will be able to live in an apartment of her own someday.

The manager is likewise sure that Karen will someday be successful at a job in the community. The manager explained that Karen had been working in the sheltered workshop when the agency found her a job at a fast food restaurant. He explained that although Karen worked at the restaurant for several months, the job did not work out and Karen returned to the sheltered workshop. The group home manager thought that some of the problems with the

job were due to the restaurant being an especially busy one where Karen might have been under pressure to work quickly. He also mentioned that Karen has a short attention span and that maybe she visited with other employees too much. He further noted that Karen's long bus ride to and from work made the job less than ideal.

Karen explained, *"I was working at Wendy's but I quit that one because it was....mostly boring....I had to toast bread, four different kinds of bread.... I told them [the adult agency] that I was getting tired of it and that I wanted to come back [to the sheltered workshop] because I was quitting."* She preferred the job at the sheltered workshop where she has friends and she wants to continue working there. Karen's mother thought that the fast food restaurant job was difficult for Karen because of the long bus ride that getting to the job required and because it made Karen too tired. She mentioned that Karen has a difficulty with incontinence and that the long bus ride only exacerbated it. She said that Karen was very ashamed after a few "accidents" on the bus ride home and that these accidents were very hard on Karen's self-esteem. She also thought that the other employees may not have been very friendly with Karen. Karen's mother prefers that Karen continue to work in the sheltered workshop where she feels that Karen will be more protected. Karen said once that she had helped her mother take care of small children and that she would really like to do more of it. When we asked if she had ever mentioned this to the agency, she said, *"No, they never brought it up."*

Unlike other parents, who have aspirations for their children to move through the agency's successive programs toward greater independence, Karen's mother does not want Karen to move out of the group home eventually. For safety reasons, Karen's mother prefers

that she stay in a group home. She also believes that her daughter needs the company of several roommates and the discipline and routine provided by the group home staff.

Karen's mother also hopes that Karen will never marry or have children. Once Karen moved into the group home, she had several boyfriends and several proposals of marriage. She evidently still calls her mother occasionally and tells her mother that someone has proposed to her and asks if she can get married. Karen's mother says no, to which Karen responds, *"Okay."* Karen's mother is able to laugh about these incidents now. According to the group home manager, the first marriage proposal came only a week or so after Karen had moved in to the group home. Karen's mother had been quite upset by it leading the manager to think that she might remove Karen from the group home. Karen's mother also had Karen placed on oral contraceptives. She is sure that Karen could not raise a child and, in her opinion, it would not be fair for her to raise Karen's child and it would not be fair to Karen if the child was smarter than Karen.

Karen's living situation is very stable. She is happy in the group home, and her mother does not want her to leave. Her employment has been considerably less stable. The group home manager sees both Karen's stay in the group home and in her current job as temporary. Karen's mother is very concerned with Karen's safety and with her experiences in the community.

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